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Acceptance and Commitment Therapy Guided Self-Help for Psychogenic Non-Epileptic Seizures

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Thesis Abstract

Psychogenic non-epileptic seizures (PNES) are a relatively common condition, however, seizures can be debilitating for patients and are associated with high levels of psychological distress, reduced quality of life and reduced functionality. Despite the debilitating effects of the condition, there is thus far no recommended treatment. Although psychological therapy is often sought following the diagnosis of PNES, there remains relatively little research in the area comparing treatment efficacy. Nevertheless, many treatment efficacy studies focus on the application of cognitive behavioural therapy to PNES and the results produced so far appear promising, however, the psychotherapeutic mechanisms of change for such therapies are less clear.

Acceptance and Commitment Therapy (ACT) is a third-wave behavioural approach based on theoretical mechanisms of change. ACT may have benefits over other traditional therapies, as its contextual approach may be more acceptable to individuals with PNES, especially if they have had difficulty in adjusting to the concept that their seizures are caused by psychological, rather than physical processes.

A single case experimental design was carried out to assess the efficacy of an ACT guided self-help intervention on psychological flexibility, psychological distress, quality of life and seizure frequency. Participants also completed a qualitative change interview at one-month follow up. The intervention was replicated six times.

All participants demonstrated an increase in psychological flexibility following the ACT self-help intervention. Four of the six participants demonstrated reliable improvements in quality of life and psychological distress. The same four participants also reported a significant decrease in seizure frequency following the intervention, with three participants reporting that they were seizure free at one-month follow-up. Triangulation of the quantitative time-series data and qualitative change interviews indicated that openness to awareness processes

(acceptance and cognitive defusion) were key mechanisms of change for individuals with PNES.

The study demonstrated the utility of an ACT treatment approach delivered in a self-help format for individuals with PNES. The implications of the study findings for future research and clinical practice are discussed.

Statement of Contribution

Journal article and extended paper

- Project design: Dr David Dawson, Dr Mark Gresswell and Ruth Barrett-Naylor
- Applying for ethical approval: Ruth Barrett-Naylor
- Recruiting Participants: Ruth Barrett-Naylor
- Data collection: Ruth Barrett-Naylor
- Creation of the Daily ACT measure (of Psychological Flexibility): Ruth Barrett-Naylor and Jenna Hunt, supervised by Dr David Dawson and Dr Mark Gresswell
- Scoring Measures: Ruth Barrett-Naylor
- Conducting the change interviews: Jenna Hunt
- Data entry: Ruth Barrett-Naylor
- Data analysis: Ruth Barrett-Naylor, supervised by Dr David Dawson and Dr Mark Gresswell
- Write-up: Ruth Barrett-Naylor, supervised by Dr David Dawson and Dr Mark Gresswell

Journal Paper

The utility of Acceptance and Commitment Therapy guided self-help for Psychogenic Non-Epileptic Seizures[1]

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Abstract

The study utilised a single case experimental design to assess the efficacy of an acceptance and commitment therapy (ACT) guided self-help intervention for people with psychogenic non-epileptic seizures. A key aim of the study was to investigate what key ACT processes influenced change in psychological flexibility, psychological distress, quality of life and seizure frequency. Six participants completed the study and reliable and clinically significant changes in psychological flexibility, quality of life, psychological distress and seizure frequency were observed in the majority of participants. Openness to experience processes (acceptance and cognitive defusion) appeared to be the most influential process in instigating change on the outcomes measured, suggesting that these processes may be helpful in producing positive effects for people with psychogenic non-epileptic seizures. The implications of these findings for clinical practice are discussed and recommendations for future research suggested.

Key Words: Psychogenic non-epileptic seizure; single case experimental design; acceptance and commitment therapy; self-help

1. Introduction

1.1. Psychogenic Non-Epileptic Seizures

Psychogenic non-epileptic seizures (PNES) are characterised by changes in consciousness and behaviour and bear a similar resemblance to epileptic seizures. Whilst epileptic seizures are caused by electro-physical changes in the brain, psychogenic non-epileptic seizures lack these changes and are underpinned by psychological processes [1,2].

Prevalence rates of PNES varies widely and affects from 2-33 per 100,000 [3]. Furthermore, approximately 20%-30% of patients who attend epilepsy centres are diagnosed with PNES [3–5], of which 75%-80% are female [4,6]. Due to some of the issues surrounding the differential diagnosis of PNES, diagnosis of PNES is often delayed (on average by 7 years) in which time patients may have received inappropriate treatment [7]. Given the delay in accurate diagnosis of PNES (and better outcomes being related to early diagnosis and access to relevant treatment [8]), it is not surprising that when patients are seen by PNES specialists, at least 25%-30% have become chronic [6], with many patients reporting reduced quality of life, reduced functionality and high levels of psychosocial distress [9–12].

[See Extended paper 1.1 for a discussion of the epidemiology and impact of PNES]

1.2. Theoretical underpinnings of PNES

PNES has a complex psychological profile and is associated with a number of psychosocial and psychological factors/mechanisms. Trauma, including historical sexual/physical abuse, bereavement and post-traumatic stress disorder (PTSD), is one of the most common factors associated with PNES [13–15]. Furthermore, PNES is associated with high levels of anxiety and depression [16–18], somatisation [19] and avoidant coping styles [20–22].

Given that patients with PNES are a large heterogeneous group, understanding PNES within a single aetiological framework is limited [6,20].

Reuber [23] suggested that PNES can be understood within a biopsychosocial, multifactorial model which accounts for the interaction of predisposing, precipitating, and perpetuating aetiologic factors commonly observed in PNES (see Figure 1). The complexity of the multifactorial model reflects the difficulties in understanding PNES in a 'one size fits all' aetiological framework, which has implications for clinical practice and the treatment provided, especially when patients are usually referred to mental health services following PNES diagnosis [24,25].

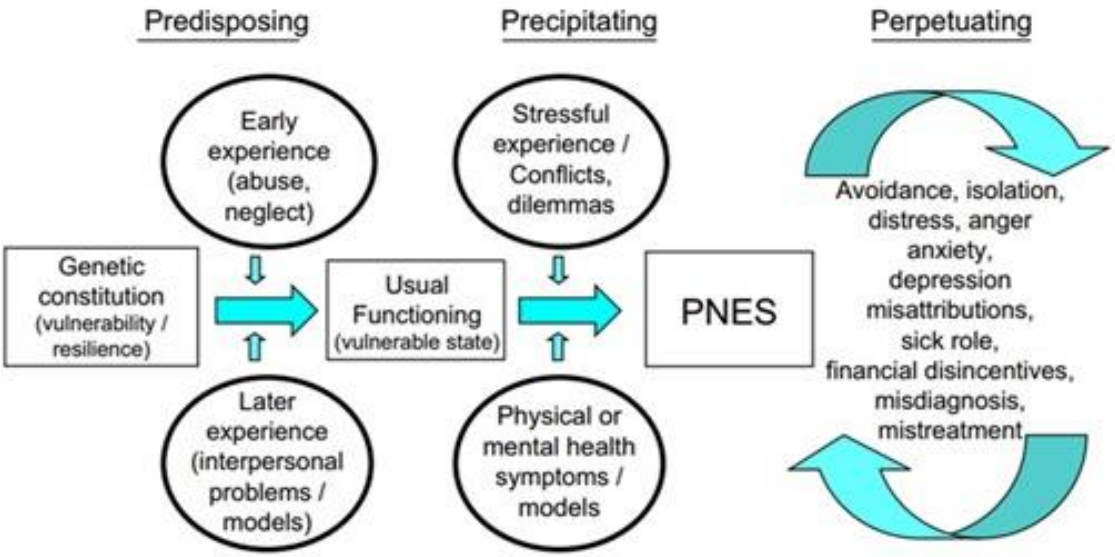


Figure 1. Aetiology of PNES: a multifactorial model [23]

Although comprehensive, the above model fails to explain why seizure-like behaviour, rather than any other specific symptom, such as irritable bowel syndrome or fibromyalgia, for example, occurs. Some authors have hypothesised that PNES occur as a result of symptom modelling, whereby organic symptoms occurring in others (or in the patients themselves), are mimicked in order to meet the primary and secondary gains of the patient [26,27]. This theory appears to be supported when epilepsy and PNES coexist within the same individual [28], or when PNES patients report that they directly

witnessed a seizure prior to the onset of their own seizures [26]. However, this does not explain the occurrence of seizure-like behaviour in individuals that do not have co-morbid epilepsy nor in those who have not witnessed a seizure prior to the onset of their own seizures [29]. The application of symptom modelling to PNES appears valid; however, as it only has a narrow focus, there remains scope for further investigation in explaining seizure-like behaviour across all individuals with PNES.

[See extended paper 1.2 for a discussion of theoretical accounts and underpinnings of PNES].

1.3. **Treatment**

Despite the condition being relatively common and having a significant impact on patients' lives, there is no current treatment recommendation for the treatment of PNES. No consensus has yet been reached regarding the most effective treatment because: *(i)* psychopathological conditions vary widely between patients with PNES [6,9,17,20,30]; *(ii)* aetiologic factors vary considerably between patients [23]; and *(iii)* there is a lack of high quality evidence evaluating the efficacy of treatments for this population [31,32]. Given the variation in aetiology and presentation in this heterogeneous group, it is not surprising that developing an effective treatment strategy for PNES is a complex task, especially when the treatment provided will largely be dependent on the existent underlying psychopathology [33].

Psychological treatments for PNES tend to be individualised interventions which focus on addressing the hypothesised mechanisms of PNES mentioned earlier [6,25,31]. Cognitive-behavioural therapy (CBT) appears to be a promising treatment for PNES, given the successful application of CBT to an expanding range of somatoform disorders, including chronic pain, chronic fatigue and medically unexplained symptoms (MUS) [34–36]. As such, CBT approaches to PNES has received much investigation [37–39].

Essentially, a CBT approach to PNES may follow much the same structure as the one described for MUS, including, disrupting vicious cycles (of interconnected cognitions, behaviours and physiological responses) which are hypothesised to perpetuate symptoms, cognitive restructuring and symptom focussing reduction [40]. Furthermore, specific features of PNES may advocate the utility of specific CBT techniques; Goldstein and Mellers [21] suggested that the paroxysmal features of PNES and associated arousal symptoms are comparative to that of panic disorder and suggest that seizures are a dissociative response ("panic without panic") to high levels of arousal caused by distressing situations. In addition, elevated levels of fear sensitivity and avoidance have been reported in PNES [20,41], which suggests that avoidance may be an important predisposing psychological mechanism underlying the condition. Therefore, treatments that are able to target avoidance may be helpful in successfully treating the condition [20].

To date, two controlled studies [42,43] and one RCT [44] have investigated the utility of a CBT approach in the treatment of PNES. These studies utilised a CBT approach consistent with the MUS model described by Deary and colleagues [35], however, the controlled study and RCT conducted by Goldstein, Deale, Mitchell-O'Malley, Toone and Mellers [42] and Goldstein, Chalder and colleagues [44], respectively, emphasised the role of avoidance within the models used. The results of these studies indicated a reduction in seizure frequency following CBT treatment and also demonstrated secondary effects in other associated psychopathological conditions, such as a reduction in depression and anxiety. However, these studies were limited in power, had limited long-term follow up data and the therapeutic mechanisms of change were not clear.

The focus of many treatment studies is to reduce or eliminate the frequency of seizures, with quality of life or functionality measures being only secondary outcomes of treatment [6,37,45]. The impact of PNES on patients' lives is an important aspect of the condition and effective strategies for managing such difficulties requires further investigation. If patients can be helped to lead meaningful, functional lives, despite their seizures, then the negative impact of

PNES may be lessened. An evidence-based psychological approach that encourages meaningful, value-based living despite having a ‘condition’ is Acceptance and Commitment Therapy (ACT; Hayes et al. [46]).

[See extended paper 1.2 for further discussion on treatment for PNES.]

1.4. **Acceptance and Commitment Therapy (ACT)**

ACT is a third wave psychological therapy which is rooted in functional contextualist philosophy [47,48]. The main aim of ACT is to increase *psychological flexibility*, which is defined as “the ability to contact the present moment more fully as a conscious human being, and to change or persist in behaviour when doing so serves valued ends” [49] (p. 7). Psychological flexibility is achieved through the core processes of ACT, which includes mindfulness and acceptance strategies and commitment and behavioural change strategies [49]. ACT suggests that both *experiential avoidance* and *cognitive fusion* give rise to human suffering. Experiential avoidance is the process of getting rid of, suppressing, or escaping unwanted private events (such as thoughts, feelings, urges, or memories) and cognitive fusion is the process of ‘fusing’ with our thoughts, for example, letting thoughts dominate our behaviour. Both experiential avoidance and cognitive fusion obstruct patients from behaving in a way that is in line with their values.

From an ACT perspective, the (psychogenic non-epileptic) seizures themselves are not the dominant problem; the problem lies within how the individual relates to their seizures, and how this in turn may prevent value-based living. For example, ‘fusing’ with the thought “I am broken” may lead the patient to limit their behaviour, avoid potentially psychologically beneficial activities, which may culminate in higher levels of suffering and distress. In other words, patients try very hard to avoid or supress the thoughts they keep fusing with; ACT theorises that this struggle functions to augment the thought, occupying all the patient’s awareness and leaving little room for anything else [49]. Unlike CBT, ACT would not attempt to control the occurrence of seizures or to alter the form or

content of thoughts, but to change the relationship patients have with their thoughts. ACT theory suggests this can lead to an increase in psychological flexibility, providing patients with psychological space to engage in valued-living [49].

According to ACT, experiential avoidance and cognitive fusion are the two main pathological processes that have the capacity to cause suffering and limit meaningful activity [50]. It is therefore no surprise that reduced quality of life is often reported by individuals with high levels of experiential avoidance and cognitive fusion [51]. An implication of the two pathological processes for PNES is that, if experiential avoidance and cognitive fusion are conceptualised as core mechanisms in the development of PNES, (indeed, previous studies have identified experiential avoidance as a core feature [21,52]) then hypothetically, an ACT approach which focuses on acceptance and value-based action could address the underlying psychological mechanisms of PNES.

[See extended paper 1.4 for a discussion on ACT and its applicability to PNES.]

1.5. **Evidence for an ACT approach**

ACT for PNES has not yet been systematically studied, however, there is already empirical support for ACT in epilepsy [53,54], chronic medical conditions, including pain [55,56], depressive disorders [57,58] and anxiety disorders [59,60]. Although the main aim of ACT is to increase psychological flexibility, secondary outcomes of therapy often result in the reduction of primary symptoms (e.g. pain, anxiety, depression etc.) [49]. Furthermore, a systematic review and meta-analysis comparing ACT and CBT for a variety of conditions (including pain, anxiety and depression) found that ACT outperformed CBT in achieving primary outcomes in nine of the sixteen reviewed studies [50]. Therefore, given the expanding evidence base for ACT and physical health conditions and the similarities PNES may share with those conditions [61,62], an ACT approach to PNES appears promising.

One case report, conducted by Baslet and Hill [63], investigated the benefits of Morita Therapy [64] (a mindfulness-based therapy (MBT), which appears to include all the elements of an ACT approach [65]) with a patient with PNES. Baslet and Hill [63] conceptualised experiential avoidance as a core mechanism of PNES and suggested that MBT techniques facilitated an attentional shift toward avoided experiences and value-based action that contributed to the positive outcomes reported in the study. Further investigation into the mechanisms of change that facilitated the successful outcomes observed in the above study is warranted, however, the preliminary findings for the efficacy of an ACT approach for PNES is promising.

The therapeutic mechanisms of change in current therapies for PNES are not well understood and previous efficacy studies are limited meaning there is scope to investigate multiple potential therapies for PNES. Baslet and Hill's [63] study suggests that therapies encompassing acceptance and valued-living strategies may be helpful in decreasing experiential avoidance and cognitive fusion in PNES patients which may lead to positive outcomes.

1.6. **Evidence for ACT self-help**

Poor engagement in psychological therapies has been reported for individuals with PNES, which may be a result of patients not attributing their seizures to psychological factors [66] or, for those that do access psychological support, because a high frequency of seizures during sessions disrupts psychotherapeutic processes [67]. Self-help interventions may address some of the issues mentioned above and there is growing support for the use of ACT delivered in a self-help format for anxiety, depression [68] and chronic pain [69].

In a recent meta-analysis and systematic review of acceptance and mindfulness based self-help interventions, Cavanagh and colleagues [68] found that significant increases in mindfulness and acceptance and reductions in primary symptoms were observed following the self-help interventions; this suggests that mindfulness and acceptance can be taught through self-help interventions

and that these processes may be beneficial for positive outcomes. Furthermore, Cavanagh et al. [68] found that guided self-help ACT approaches were more effective than non-guided self-help, which is in line with findings from other self-help studies utilising alternative therapy models [70–73].

[See extended paper 1.5 for discussion of self-help approaches]

The use of ACT as a therapeutic intervention for patients with PNES is still very much in its infancy, however, the theoretical applicability of an intervention such as ACT for this population, in which avoidance of internal states and disruptions to valued-behaviour occur, appears promising. Other treatments that attempt to reduce seizures through increased cognitive control (as in CBT) have proven difficult and may not be effective for all patients in the longer term [32]. The current study therefore aimed to extend and expand existing knowledge in this area and consider the efficacy of a guided self-help ACT intervention as a treatment for people with PNES.

A single case experimental design (SCED) was employed to examine the processes of change in using ACT for the treatment of PNES on an individual level and across multiple participants. A SCED was chosen due to its ability to identify therapeutic mechanisms of behaviour change and focus on individual differences; an advantage over group designs especially when the population being investigated is highly heterogeneous.

[See Extended paper 2.2.2 for further discussion of SCEDs]

1.7. **Aims and purpose of investigation**

The purpose of the study was to examine the effects of a guided self-help ACT intervention in participants with PNES, including effects on psychosocial distress, quality of life and seizures.

The studies main research questions were:

- Which ACT processes are mechanisms of change for PNES phenomena as a whole (including psychosocial distress, quality of life and seizure frequency);
- Does a self-help ACT intervention have an effect on:
  - Self-report measures of quality of life
  - Psychosocial distress and behavioural outcomes (e.g. seizures)

[See extended paper 1.6 for a discussion of the clinical relevance of this study.]

2. Method

2.1. Participants

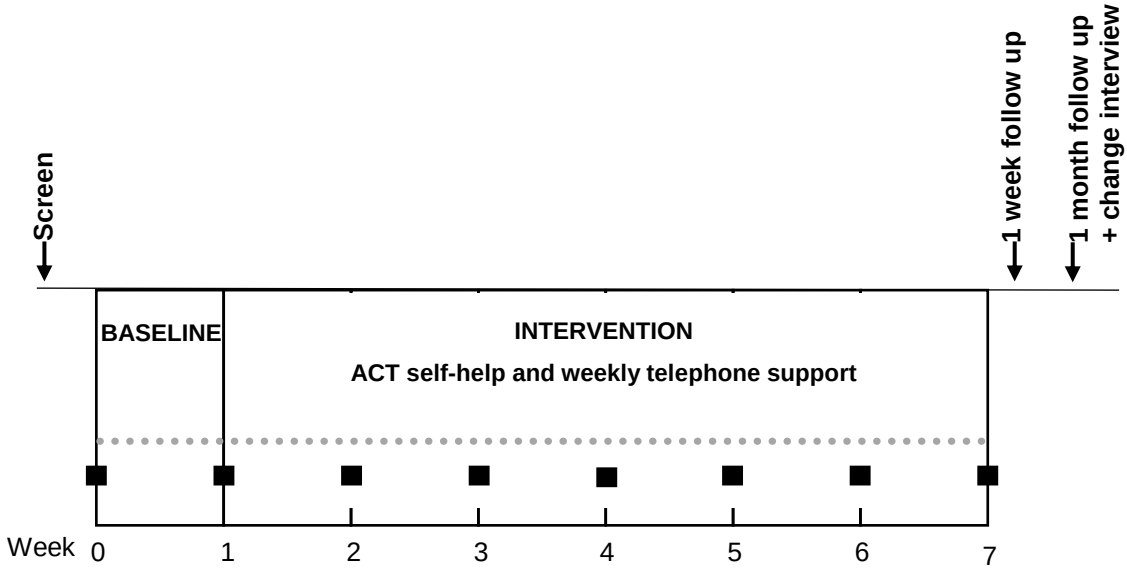
Prospective participants were recruited from specific PNES social media groups. When prospective participants responded to the advertisement they were sent the participant information sheet (see Appendix A) to provide further information about the study. After having read the information sheet and agreeing to take part in the study, participants were asked to complete an online consent form (see Appendix B) and an online screening questionnaire to ensure they met the following inclusion criteria:

1. ≥ 18 and able to provide informed consent.
2. Confirmed diagnosis of PNES
3. ≥ 3 psychogenic non-epileptic seizures in the past month.
4. Not currently receiving, or about to receive, psychotherapy (participants were considered if they were in receipt of counselling that was not directly related to seizures or associated seizure difficulties).
5. Have a good understanding of the English language, including reading and comprehension (assessed by the researcher in initial correspondence and telephone contact).

[See extended paper 2.1 for a more detailed discussion of the inclusion criteria and extended paper 4.3.1 for a critical discussion of sampling considerations including the recruitment process]

2.2. **Study design and procedure**

To investigate the efficacy of an ACT intervention for PNES, a non-concurrent multiple baseline A-B SCED series was used [74,75]. If participants agreed to take part and met the inclusion criteria, they completed a battery of questionnaires online before completing a non-treatment baseline for a minimum of 5 days [76]. During the baseline, participants completed a daily ACT process measure online until a stable or declining trend in psychological flexibility was established (see measures). When a stable baseline was reached (characterised by a stable or declining trend in psychological flexibility), participants completed a battery of questionnaires (again online) before starting the intervention phase of the study. As participants came forward to take part in the study over a four-month period, no participant began the study at the same time, which satisfied the multiple (non-concurrent) baseline design of the study. The average number of participants used in SCED research is six [74], therefore recruitment continued until at least 6 participants had completed the study. (See
Figure 2 for an overview of the SCED design).



Notes: ····· = daily measures completed; ■ = weekly measures completed; Follow-up=weekly measures completed

Figure 2. Overview of the SCED used in the current study

[See Extended paper 2.2 for an in-depth discussion on SCED research and the epistemological position taken].

2.3. **Measures**

Daily and weekly measures of quality of life, psychosocial distress, seizure frequency and core ACT processes were administered throughout the study. All measures were completed online.

2.3.1. Weekly measure

Participants were required to complete a battery of weekly measures on commencement of the study, throughout the six weeks of the intervention, and again at follow up.

In relation to psychological flexibility, there is considerable overlap between the six core ACT processes [77], therefore the measures chosen (i.e. the Comprehensive Assessment of Acceptance and Commitment Processes (CompACT)) were designed to access the three key ACT processes outlined by Hayes, Villatte, Levin and Hildebrandt [78]: *Openness to Experience*

(acceptance and defusion), *Behavioural Awareness* (present moment awareness and self as context) and *Valued Action* (values and committed action), as well as overall psychological flexibility (see Table 1.)

2.3.2. Daily measure

Participants completed a brief daily questionnaire to record consistent time series data (see Appendix C). The daily questionnaire was designed to capture information regarding the participant's frequency of seizures, overall mood and psychological flexibility. Three items were taken from the DASS-21 (1 item from each subscale based on highest factor loading) which comprised the daily overall mood measure. Similarly, the brief psychological flexibility measure comprised of six items from the CompACT (2 items from each of the 3 key process areas) and were chosen on highest factor loading and face validity. Furthermore, the brief CompACT also formed the baseline measurement prior to beginning the intervention phase of the study.

[See extended paper 2.3 for further discussion on how the measures were selected and completed (online)]

Table 1. Psychometric properties and characteristics of measures

	Construct	No. item	Example item	Int. c	Scale range & direction
Weekly Measures					
DASS 21 [79]	Overall distress	21		.93	0 – 126
	Depression	8	"I felt down hearted and blue"	.88	0 – 42
	Anxiety	8	"I felt I was close to panic"	.82	0 – 42
	Stress	8	"I tended to over react to situations"	.90	0 – 42 lower score = less distress
QOLIE 10 [80]	Quality of life	10	"How much did your work/social limitations bother you" / "How worried are you about having a seizure"	.85[#]	10 – 50 Lower score = better QoL
CompACT [81]	PF	23		.91	25 – 137
	OE	10	"I tell myself I shouldn't have certain thoughts"	.90	1 – 60
	BA	5	"I find it difficult to stay focused on what's happening in the present"	.87	1 – 30
	VA	8	"I make choices based on what is important to me, even if it is stressful"	.90	4 – 48 Higher score = higher PF
AAQ II [82]	PF and acceptance	7	"Emotions cause problems in my life"	.84	7 – 49 lower score = higher PF
Daily measures					
D-CompACT	Daily PF	6	"I rush through meaningful activities without being attentive to them" (BA); "I work hard to keep out upsetting feelings" (OE); "my values are really reflected in my behaviour" (VA)	-	0 – 36 Higher score = higher PF
D-DASS	Daily psychosocial distress	3	"I felt that life was meaningless"; "I was aware of the action of my heart despite any physical exertion"; "I was intolerant of anything that got in the way of what I was doing"	-	0 – 18 lower score = less distress
Seizure frequency	Daily No. seizures	-		-	-

Notes: DASS 21=depression anxiety & stress scale; QOLIE-10=quality of life in epilepsy inventory; CompACT=comprehensive acceptance and commitment therapy processes; AAQ II=acceptance & action questionnaire; D-=daily; PF=psychological flexibility; OE=openness to experience; BA=behavioural awareness; VA=valued action; Int.c=internal consistency; No.=number of; [#]translated measure used as higher inter cons [83].

In the intervention phase, participants worked through chapters of the self-help book, *Get out of your mind and into your life* [84] over six weeks. The chapters of the workbook were arranged so that participants worked through one of the six core ACT processes each week (see Table 2).

Table 2. Participant reading materials and ACT process measured.

Week	ACT process	Chapter number	Chapter title(s)
Baseline (Overview of ACT given after screen completed)	N/A	Intro, 1, 2	Introduction; Human suffering; Why Language leads to suffering
1	Acceptance	3, 4, 9, 10	The Pull of Avoidance; Letting go; What Willingness is and what it is not; Willingness; Learning to Jump
2	Cognitive Defusion	5, 6	The trouble with Thoughts; Having a Thought vs. Buying a Thought
3	Self as Context	7	If I'm not my Thoughts, the Who Am I?
4	Present Moment Awareness	8	Mindfulness
5	Values	11, 12	What are Values?; Choosing Your Values
6	Committed Action	13	Committing to Doing It

Telephone support was provided by the researcher once a week (for up to 30 minutes); this involved a discussion relating to the material read over the past week and any particular difficulties the participant had had (this included difficulties with understanding concepts or exercises and any external events in the person's life which may have impacted on their ability to complete the self-help material).

During the intervention phase, participants completed measures daily (daily measure) and weekly (battery of weekly questionnaires). Participants completed the weekly battery of questionnaires again at one week and one month following the end of the intervention.

At the one month follow up period, a change interview [85] was conducted by an independent researcher, who was blinded to the results of the study. The change interview was designed to assess participant's views on the workbook, how they felt about completing the study, their perception of any changes related to seizure frequency and quality of life, and the possible reasons for any changes.

[See Extended paper 2.4 for further discussion of the procedure of the study]

The current study was reviewed and granted ethical approval by the University of Nottingham School of Medicine Research Ethics Committee. (See Appendix D)

[See Extended paper 2.5 for a discussion on ethical considerations]

2.4. **Analysis**

To address the first research question (which ACT processes are mechanisms of change for PNES phenomena), visual analysis of the SCED time series data was used to identify when and where during the intervention changes occurred in PNES phenomena (seizures, distress, quality of life); this facilitated investigation of possible mechanisms of change in PNES phenomena in relation to the stage of the intervention and whether a relationship between PNES related phenomena and psychological flexibility was also observed. In order to evaluate the SCED data, parameters of central tendency, variability, trend, overlap and point of change for daily psychological flexibility was analysed [86] (See Appendix E for a graphical example of parameters).

In order to answer the second research question of the study (does a self-help ACT intervention effect PNES phenomena), the pre-, weekly, post and follow-up scores were analysed to determine if there had been any changes in self-reported seizure frequency, quality of life, psychosocial distress and psychological flexibility throughout the course of the intervention. To establish whether these changes were reliable (at a 95% confidence interval), Reliable

Change Index (RCI) and Clinically Significant Change (CSC; criterion c or a) [87] methods were applied to the data (see Table 3).

Table 3. RCI Values and CSC cut-off Scores Applied to the Self-Reported Weekly Measures

Measure	Critical RCI Value	CSC cut off (+/-)
DASS 21 (Psychological distress)[2]	14.43 (NB)	24.43 (NB) (-)
	14.03 (PB)	28.39 (PB) (-)
QOLIE-10 (Quality of Life)	1.49	24.90 (-)
CompACT (Psychological flexibility)	26.69	26.69 (+)
AAQ II (Psychological flexibility)	8.95	8.35 (-)

Notes: Individual change scores must be more than the RCI value in order to be statistically significant at 0.05 level. In order for individual change scores to be both reliably and clinically significant, they must change by more than the RCI value and cross the CSC cut off; (-) scores must fall below or (+) above the CSC value stated.

DASS 21= depression, anxiety & stress scales; QOLIE-10= quality of life in epilepsy; AAQ-II= acceptance & action questionnaire; NB=no burden; PB= psychological burden; RCI= reliable change index; CSC= clinically significant change.

[See extended paper 2.6 for further discussion of RCI and CSC methods.]

In order to evaluate the treatment effect size of the intervention, Percentage Exceeding the Median (PEM) methods were used when analysing the graphical data [88]. The effect size was produced by calculating the percentage of data points on the daily measure that exceeded the participant's median baseline score. The daily CompACT measure was used to calculate the PEM, given the available number of data points throughout the baseline phase and because psychological flexibility was the construct of interest. PEM scores of 90% or above were deemed as highly effective, between 90% and 70%; moderately effective, and below 70%; not effective.

[2] The comparison sample used to calculate RCI/CSC for the DASS 21 divided patients into subgroups dependant on whether they had a predominant psychiatric profile 'psychological burden' (psychiatric diagnoses of anxiety/depression etc.), predominant neurological profile 'neurological burden' (i.e. comorbid epilepsy, stroke etc.) or if they did not appear to have either, 'no burden' [18]. The participants in the current study were divided into groups based on the profiles suggested by Baslet et al. [18] in order to calculate RCI/CSC. [See extended paper 2.6.4 for more information regarding the subgroups for the DASS 21].

Change interview responses from each participant were used to support or contest quantitative findings regarding the effects of the ACT intervention with PNES phenomena and help evaluate whether any part of the workbook was particularly influential for participants regarding any perceived changes. In addition, the findings from the change interview were helpful in considering extraneous factors to the treatment process.

3. Results

3.1. Sample

Seven participants took part in the study. One participant withdrew after the third week and their data was not included in the analysis. Table 4 shows the sample demographics of the remaining six participants who took part in the study.

Table 4. Demographics of sample

P	Age	Gender	M/H diagnosis	Prev. EP	Current EP	PNES diagnosis received	Medication for PNES	Prev. psych. treatment
1	69	M	N	N	N	March 2015	N	N
2	24	F	Depression Anxiety	N	N	April 2016	N	N
3	53	F	N	Y	N	May 2013	N	N
4	47	F	Anxiety	N	N	November 2011	Amitriptyline (muscle relaxant)	ISTDP "Talking therapy"
5	32	F	N (reported symptoms of anxiety and depression)	N	N	July 2015	N	N
6	47	F	Complex PTSD Depression	Y	N	2012	Klonopin	Progressive exposure

Notes: P=participant; M/H diagnosis= mental health diagnosis; PTSD= Post traumatic stress disorder; Prev. EP= previous diagnosis of epilepsy; EP=epilepsy; PNES= psychogenic non-epileptic seizures; Prev. Psych. treatment= previous psychological treatment; ISTDP=Intensive short term dynamic psychotherapy

All but one of the participants in the study were female and the average age of participants was 45.3 (SD=15.86). Two participants had previously received a diagnosis of epilepsy; however, their diagnosis was changed to PNES later. The time since PNES diagnosis across participants ranged from November 2011 to April 2016. Three participants reported having a mental health diagnosis (including anxiety, depression and/or PTSD) and one participant reported having symptoms of anxiety and depression. Two participants reported taking medication to help with their seizures and two participants reported receiving previous psychological therapy.

3.2. **Battery measures and results**

Responses to all the weekly measures at pre, post and follow-up are presented in the table below (see Table 5). Clinically reliable and significant change methods were used to demonstrate any changes from pre-treatment to post and follow-up scores.

Table 5. Results of CompACT; AAQ-II; QOLIE-10; DASS-21

Participant	Time	CompACT	C-OE	C-BA	C-VA	AAQ-II	QOLIE-10	DASS-21	D-ANX	D-DEP	D-STR
P1	Pre	100	45	25	30	12	16	10	2	4	4
	Post	120	52	28	40 R+ C+	12	12	10	2	4	4
	1 week	117	50	27	40 R+ C+	10	10	6	4	0	2
	1 month	120	52	27	41 R+ C+	10	14	10	2	2	6
P2	Pre	49	19	4	26	26	39	78	26	28	24
	Post	116 R+ C+	49 R+ C+	25 R+ C+	42 R+ C+	12 R+	13 R+ C+	16 R+ C+	8 R+	2 R+ C+	6 R+ C+
	1 week	117 R+ C+	49 R+ C+	26 R+ C+	42 R+ C+	12 R+	14 R+ C+	20 R+ C+	4 R+ C+	6 R+ C+	10 R+ C+
	1 month	106 R+ C+	40 R+ C+	24 R+ C+	42 R+ C+	13 R+	17 R+ C+	32 R+	6 R+ C+	16 R+	10 R+ C+
P3	Pre	125	49	30	46	15	20	12	2	2	8
	Post	129	57	30	42	14	19	6	0	4	2
	1 week	138	60	30	48	11	14	2	0	0	2
	1 month	137	60	30	47	10	12	10	0	0	10
P4	Pre	40	17	4	19	35	30	68	20	22	26
	Post	106 R+ C+	45 R+ C+	23 R+ C+	38 R+ C+	23 R+	16 R+ C+	30 R+	8 R+	8 R+ C+	14 R+
	1 week	116 R+ C+	50 R+ C+	27 R+ C+	39 R+ C+	13 R+	12 R+ C+	14 R+ C+	4 R+ C+	2 R+ C+	8 R+ C+
	1 month	120 R+ C+	55 R+ C+	25 R+ C+	40 R+ C+	14 R+	10 R+ C+	12 R+ C+	2 R+ C+	2 R+ C+	8 R+ C+
P5	Pre	47	13	7	27	29	31	56	24	10	22
	Post	138 R+ C+	60 R+ C+	30 R+ C+	48 R+ C+	7 R- C-	19 R+ C+	16 R+ C+	4 R+ C+	2 R+ C+	10 R+ C+
	1 week	130 R+ C+	53 R+ C+	29 R+ C+	48 R+ C+	7 R- C-	19 R+ C+	10 R+ C+	2 R+ C+	2 R+ C+	6 R+ C+
	1 month	137 R+ C+	60 R+ C+	29 R+ C+	48 R+ C+	7 R- C-	15 R+ C+	2 R+ C+	2 R+ C+	0 R+ C+	0 R+ C+
P6	Pre	50	10	6	34	28	35	34	4	12	18
	Post	118 R+ C+	47 R+ C+	25 R+ C+	46 R+ C+	20 R+	29 R+	18 R+ C+	2	2 R+ C+	14
	1 week	116 R+ C+	51 R+ C+	21 R+ C+	44 R+ C+	12 R+	33 R+	28	6	8	14
	1 month	121 R+ C+	51 R+ C+	25 R+ C+	45 R+ C+	17 R+	30 R+	24	2	6	16

Notes: C-OE=CompACT openness to experience; C-BA= CompACT behavioural awareness; C-VA= CompACT valued action; AAQ-II=Acceptance& Action questionnaire; QOLIE-10= Quality of Life in Epilepsy; DASS-21= Depression Anxiety & Stress scale; D-ANX= DASS anxiety subscale; D-DEP= DASS depression subscale; D-STR= DASS stress subscale.

R denotes Reliable Change at p<.05; C denotes Clinically Significant Change (from clinical to non-clinical range); + or - indicates improvement or deterioration, respectively. (N.B. all scales used criterion c for clinical cut off except AAQ-II which used criterion a).

3.3. **Clinically Significant and Reliable Change- Full Scale Measures**

Clinically significant and reliable change index scores (CSC; RCI, respectively) were calculated for the measures of psychological distress (DASS-21), quality of life (QOLIE-10) and psychological flexibility (CompACT & AAQ-II) (see Figure 3-Figure 6).

On all outcome measures (except the AAQ II), participant 1 (P1) and participant 3 (P3) scored within the normal range for a non-distressed population; as such, any improvements in their scores could not be deemed reliable. The following section focuses on participants whose scores were within the clinical cut off range of a clinical population.

3.3.1 Participant 2 (P2)

P2 showed reliable and clinically significant change on their QOLIE-10 and CompACT scores at both post-treatment and follow-up. Although a slight deterioration in her score was observed at follow-up in comparison to her post-treatment score, her scores still fell within the clinically significant and reliable range. Comparable to the CompACT, her change scores on the AAQ-II were reliable but were not clinically significant. P2 also showed clinically significant and reliable change in her scores on the DASS-21, however, at the one-month follow-up, her score fell within the range of a clinical population rather than non-clinical, although changes were still deemed reliable.

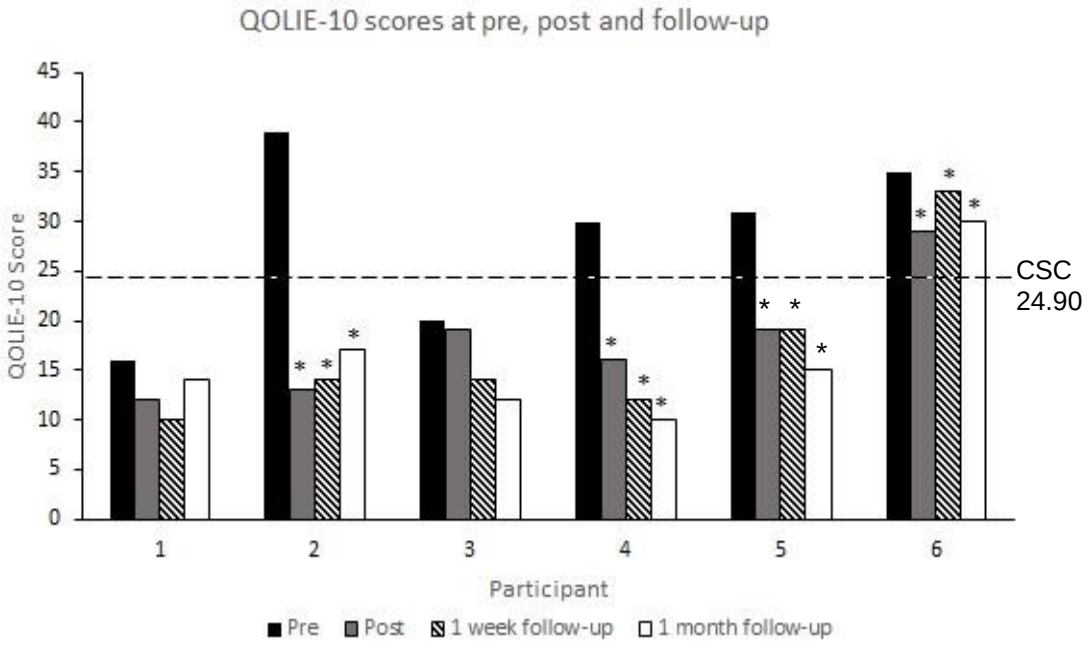
3.3.2 Participant 4 (P4) and Participant 5 (P5)

P4 and P5 showed clinically significant changes and reliable improvements on their QOLIE-10, DASS-21 and CompACT scores at post-treatment. In addition, these improvements were observed to be clinically significant and reliable at follow-up. On the AAQ-II, P4's change scores were reliable, though not clinically significant, whereas P5's scores on the AAQ-II were both clinically significant and reliable at post-treatment and follow-up.

3.3.3 Participant 6 (P6)

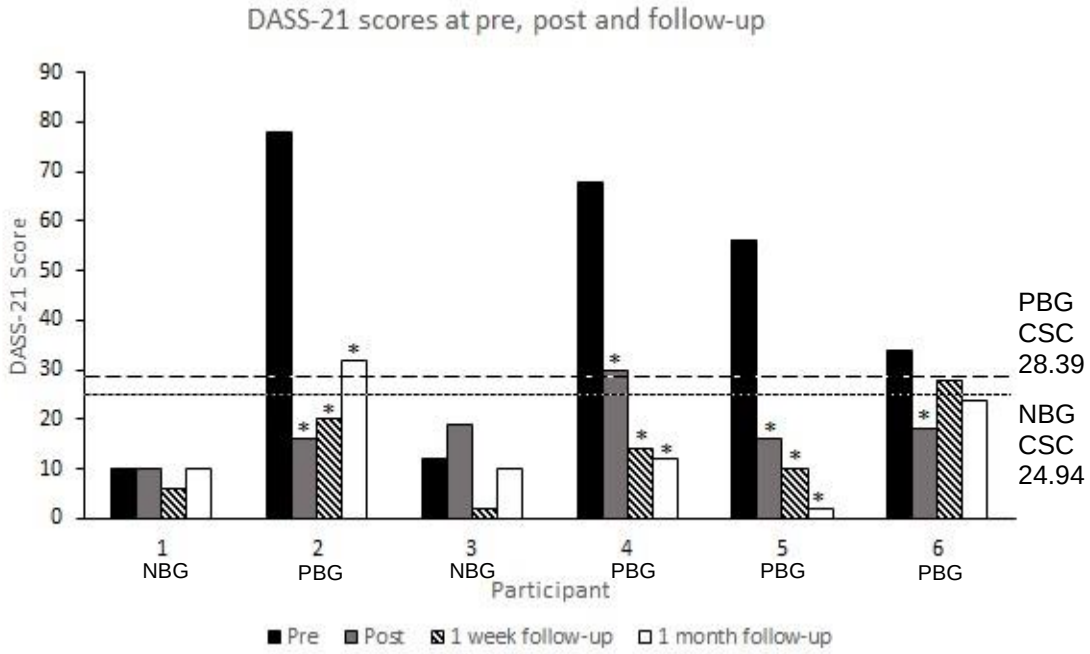
On the QOLIE-10, P6 showed a reliable improvement in her score at post-treatment and at follow up, however, although her scores were deemed to be reliable, these changes were not clinically significant. Furthermore, her scores on the DASS-21 were clinically significant and reliable at post-treatment, however, at follow-up, the changes were not deemed as reliable even though they fell within the clinically significant range. Her scores on the CompACT were observed to be both clinically significant and reliable at all time points following the intervention, whereas she only made reliable changes on her AAQ-II scores at follow-up.

[See extended paper 3.3.1. for further analysis of the DASS-21 subscales at pre, post and follow-up]



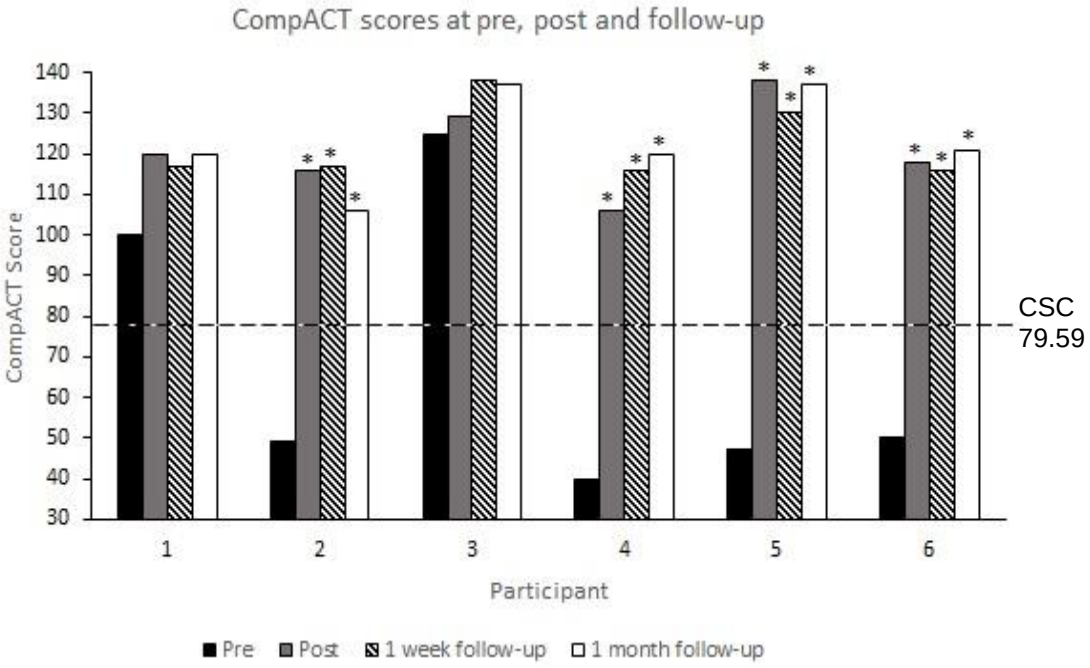
Notes: scores must fall below cut-off score for changes to be significant; CSC=clinically significant change (criterion c); * reliable change from pre-treatment score (change greater than RCI value=1.49).

Figure 3. Chart showing RCI and CSC for QOLIE-10 outcome measure



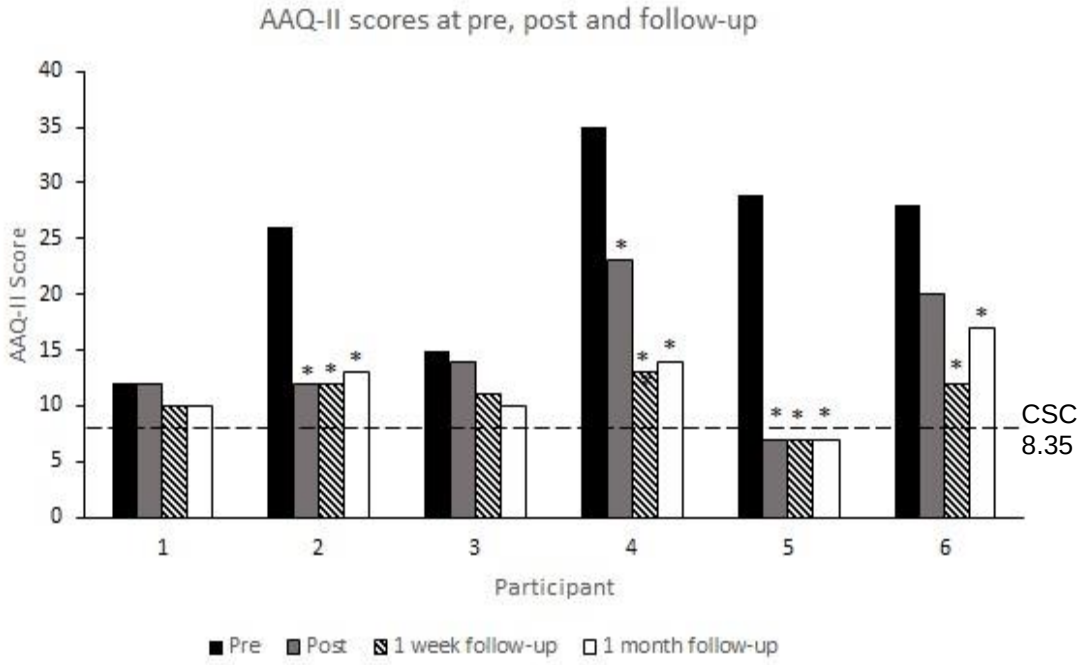
Notes: scores must fall below CSC cut-off score for changes to be significant; CSC=clinically significant change (criterion c); * = reliable change from pre-treatment score (change greater than RCI value = 14.43 (NBG)/ 14.03 (PBG).

Figure 4. Chart showing RCI and CSC for DASS-21 outcome measure



Notes: scores must fall above CSC cut-off score for changes to be significant; CSC=clinically significant change (criterion c); * reliable change from pre-treatment score (change greater than RCI value=26.69)

Figure 5. Chart showing RCI and CSC for CompACT outcome measure



Notes: scores must fall below CSC cut-off score for changes to be significant; CSC=clinically significant change (criterion a); * reliable change from pre-treatment score (change greater than RCI value=8.95)

Figure 6. Chart showing RCI and CSC for AAQ-II outcome measure

[See Extended paper 3.1 for an analysis of the weekly outcome measures]

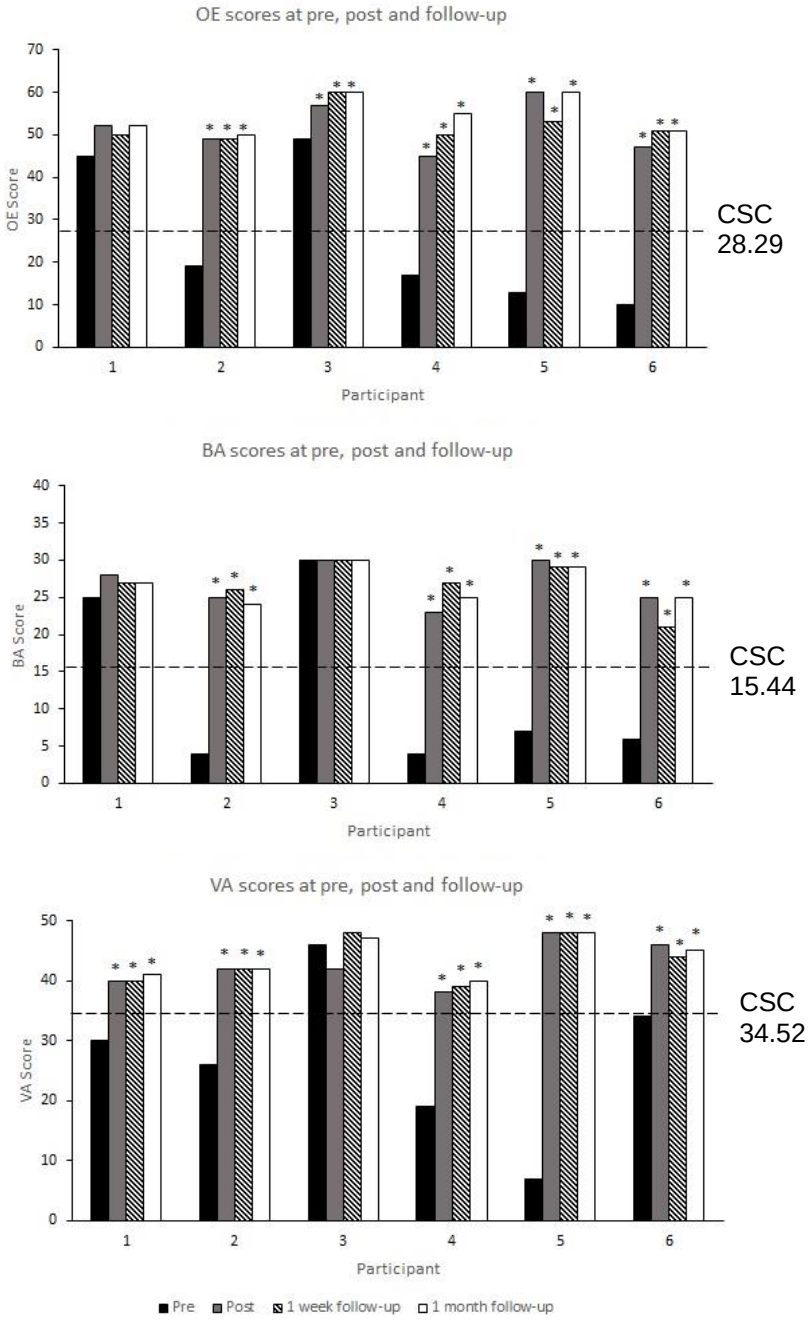
3.4. **Reliable and Clinically significant change: Subscales**

3.4.1 ACT Processes

Reliable and clinically significant changes were calculated for the ACT processes as measured by the CompACT subscales (i.e. Openness to Experience (OE), Behavioural Awareness (BA) and Valued Action (VA) subscales).

Reliable and clinically significant changes were observed in *acceptance* and *cognitive defusion* processes for all participants (except P1 and P3) as measured by the OE subscale of the CompACT. Similarly, clinically significant and reliable change was found in all but two cases (P1 and P3) on the *present moment awareness* process (measured by the BA subscale). ACT processes of *values* and *committed action* (as measured by the VA subscale) increased

reliably and clinically significantly in five cases (P1, P2, P4, P5 and P6) (see Figure 7).



Notes: scores must fall above CSC cut-off score for changes to be significant; CSC=clinically significant change (criterion c); OE= openness to experience; BA= behavioural awareness; VA= valued action; * reliable change ≥ RCI value: 13.6 (OE), 10.68 (BA), 7.31 (VA)

Figure 7. Bar chart showing OE, BA and VA outcomes

[See Extended paper 3.2 an analysis of the weekly ACT processes and 3.3.2 for an analysis of the weekly DASS-21 subscales]

[See Extended paper 3.4 for an overall synthesis of these results]

3.5. **Time series visual analysis**

Each participant's scores on the D-SF, D-CompACT, DASS-21 and QOLIE-10 during baseline, intervention and follow-up (exception of D-SF at follow up; for weekly seizure frequencies see
Figure 14) are shown in Figure 8 to Figure 13 . The baseline phase for all participants show either a stable or declining baseline on the D-CompACT measure.

Most participants showed an increase on their CompACT score between the baseline phase and first intervention phase, indicating an increase in psychological flexibility; whereas P1 and P3 showed a decrease in their score. P1 and P2 showed the largest increase in their CompACT score after the acceptance phase (N.B. The acceptance phase was the first intervention phase for all participants except for P1, where it was the second intervention phase); P6 showed a rapid increase in her CompACT score following the cognitive defusion phase (2nd intervention phase); and P3 and P5 showed a rapid increase in their scores following the self-as-context phase (3rd intervention phase). For all participants, after this rapid increase occurred, their scores generally continued to rise and stabilise throughout the study and remained relatively stable through till follow-up. Furthermore, a downward trend (indicating improvement) was observed for all participants on the QOLIE-10 measure and on the DASS-21 measure (except P1, whose slight upward trend on the DASS 21 indicated an increase in psychological distress).

In relation to daily self-reported seizure frequency, it appeared that half the participants (P2, P4 and P5) experienced fewer seizures as the study progressed, whereas it was less clear whether seizure frequency improved for

the other participants. Although a reduction in seizure frequency for these participants was not observed, there appeared to be an improving trend for psychological flexibility and quality of life, despite seizures, resulting from the ACT intervention.

In relation to the D-CompACT measure across the time series, it did not appear that this related directly to the scores on the weekly CompACT measure for half of the participants (P1, P3 and P4); either the D-CompACT scores appeared relatively stable throughout whereas the weekly CompACT scores suggested improvement, albeit not a statistically significant improvement (P1 and P3), or where the D-CompACT scores appeared to fluctuate dramatically across each week but were not congruent with the weekly CompACT scores (P4). However, the D-CompACT scores for P2, P5 and P6 did appear to correlate somewhat with the weekly CompACT score. The items selected for the brief CompACT measure may need further evaluation in order to assess its reliability and validity in relation to its parent form, the CompACT.

The calculation of treatment effect using Ma's PEM method [88] indicated an average treatment effect size of .79; this suggests that, overall, the treatment had a moderate effect on increasing psychological flexibility (see Table 6). Treatment was considered 'highly effective' for P4 and P6, 'moderately effective' for P1 and P2, and 'not effective' for P3 and P5.

Table 6. Treatment effect sizes for each participant

Participant	Treatment effect	Interpretation
P1	.87	Moderately effective
P2	.82	Moderately effective
P3	.45	Not effective
P4	1.0	Highly effective
P5	.62	Not effective
P6	.96	Highly effective

Triangulation of the qualitative data obtained from the weekly telephone support and the time series data illustrated that on commencement of the study, all participants disclosed that they wanted their seizures to stop, all but two participants reported feelings of distress related to their seizures or thoughts about their seizures, and all participants reported that seizures (in addition to other symptoms, such as pain; P2 and P3) were preventing them from engaging in activities that were meaningful to them, for example, P1 reported that he "had to give up driving and [his voluntary role]" and that seizures "stop [him] from doing things around the house; [he] can only do DIY when [he] feels able" and P2 reported that she "gets sent home from work if [she] has a seizure" and that she "can't go out on [her] own". In addition, P2 and P3 reported the occurrence of negative external events during the study (see Table 7); inspection of the weekly telephone support notes indicated that the distressing external family event for P3 occurred during the Values phase of the study; triangulation of this event with the time series data highlighted that psychological flexibility was not significantly impacted upon during this time, even though this would have been a highly emotive time for P3. Thus, reanalysis of the quantitative and qualitative data in this way provides further support for the utility of ACT in facilitating the management of distress related to seizures, thoughts or other distressing life events. Similar findings were also observed across all other participants, where despite the occurrence of seizures (acquired through quantitative data collection), thoughts, feelings or memories (that were reported during the weekly telephone support), a continuous rise in psychological flexibility was observed.

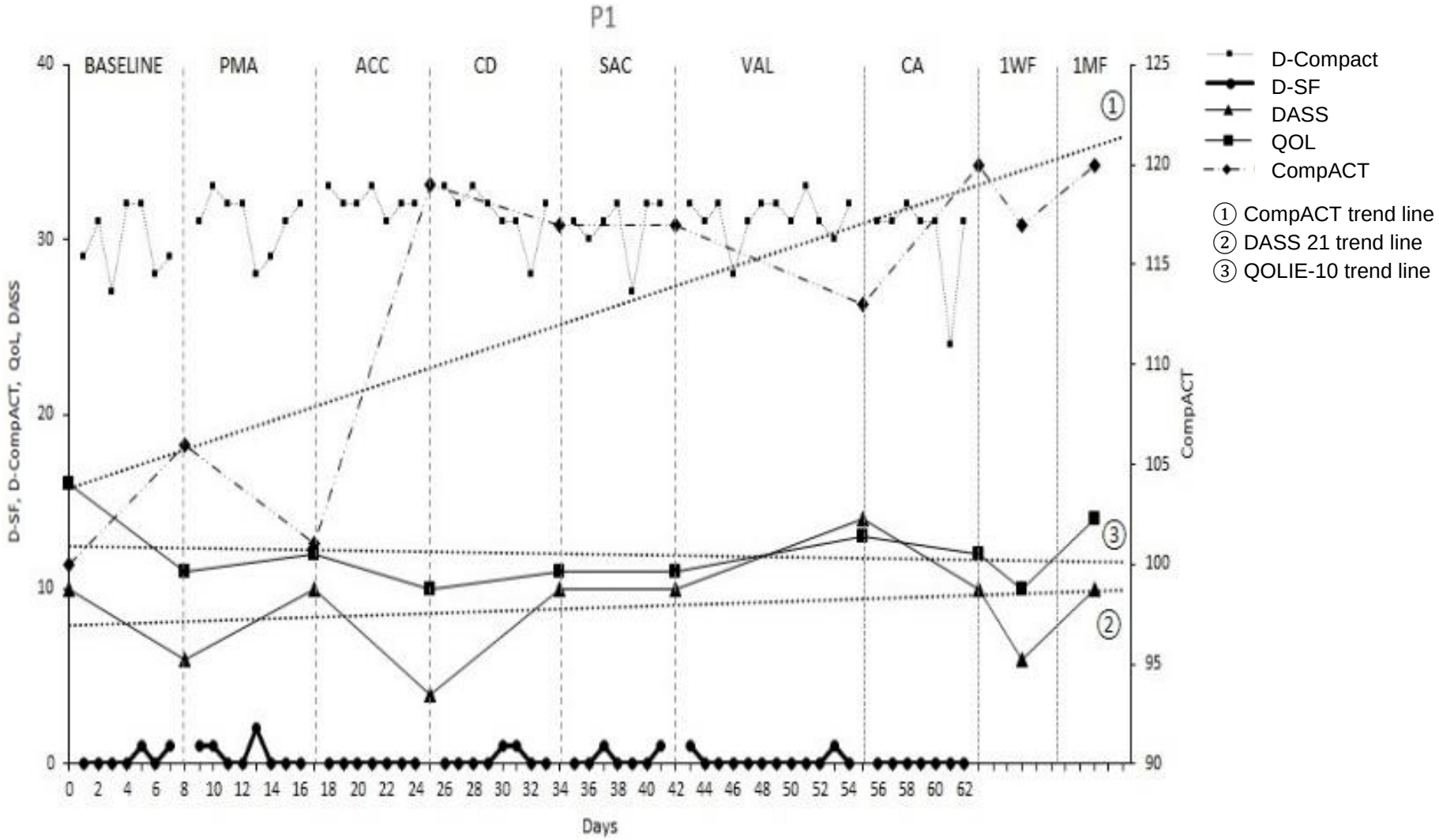


Figure 8. Time series data for Participant 1

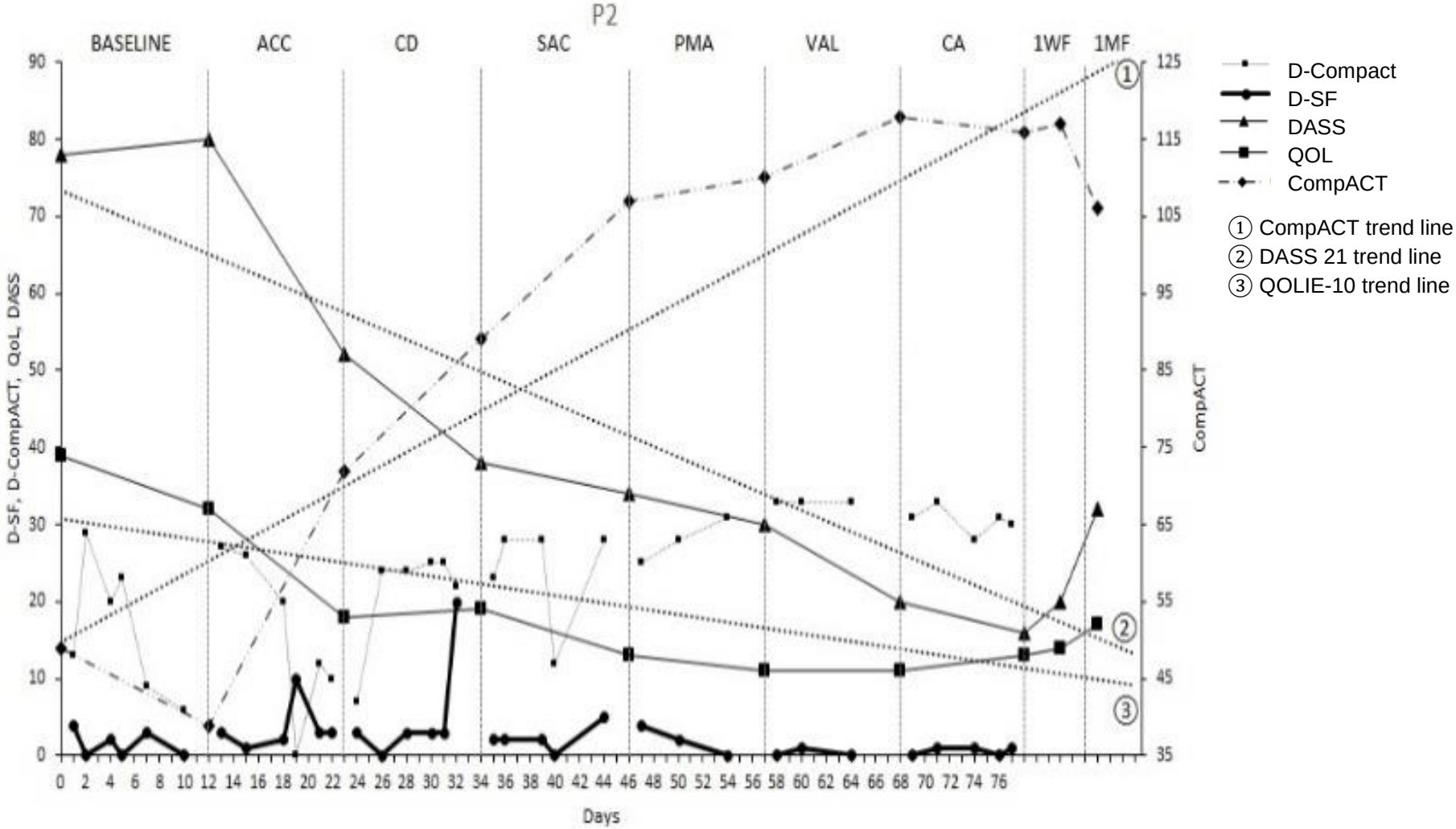


Figure 9. Time series data for Participant 2

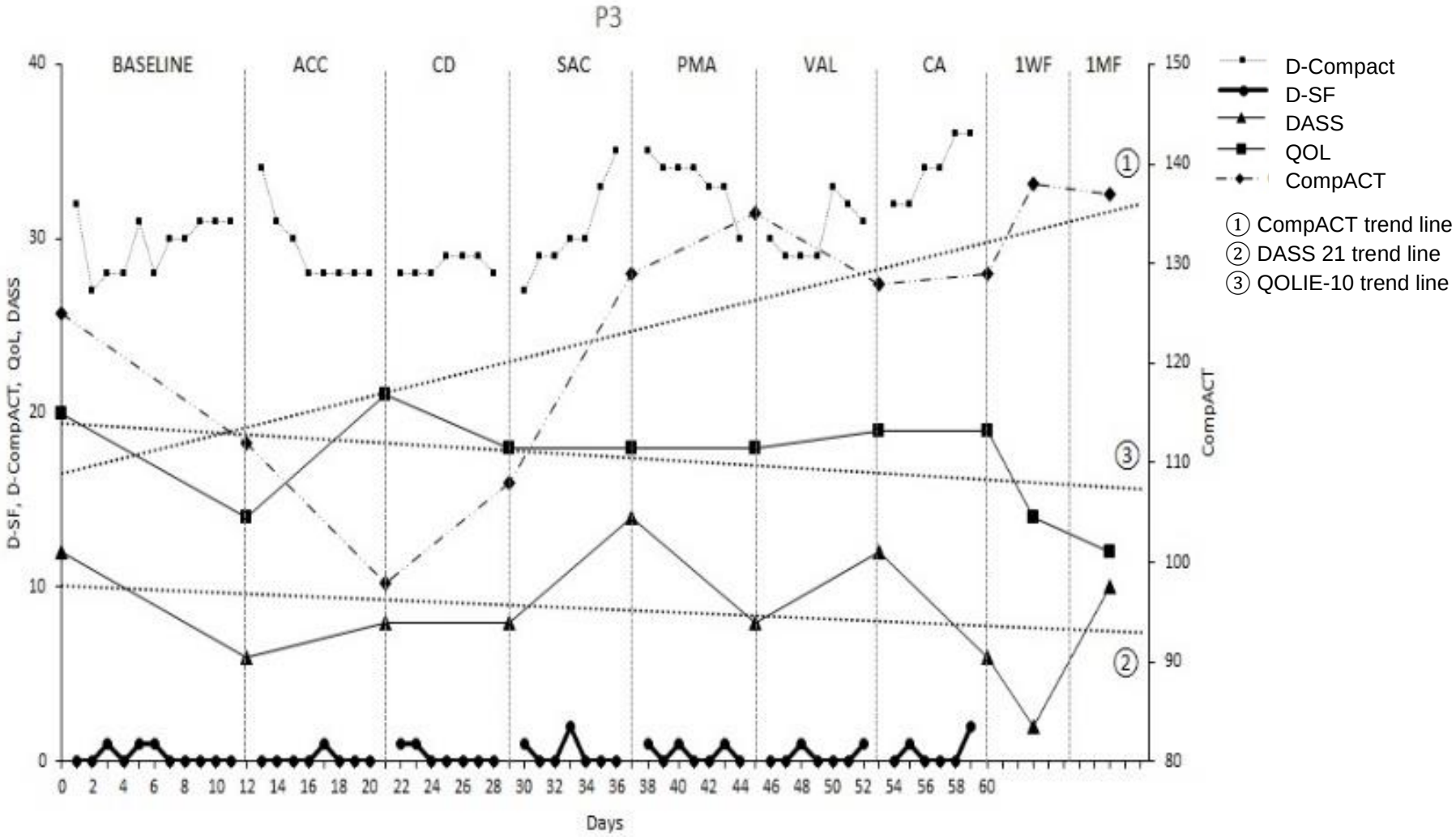


Figure 10. Time series data for Participant 3

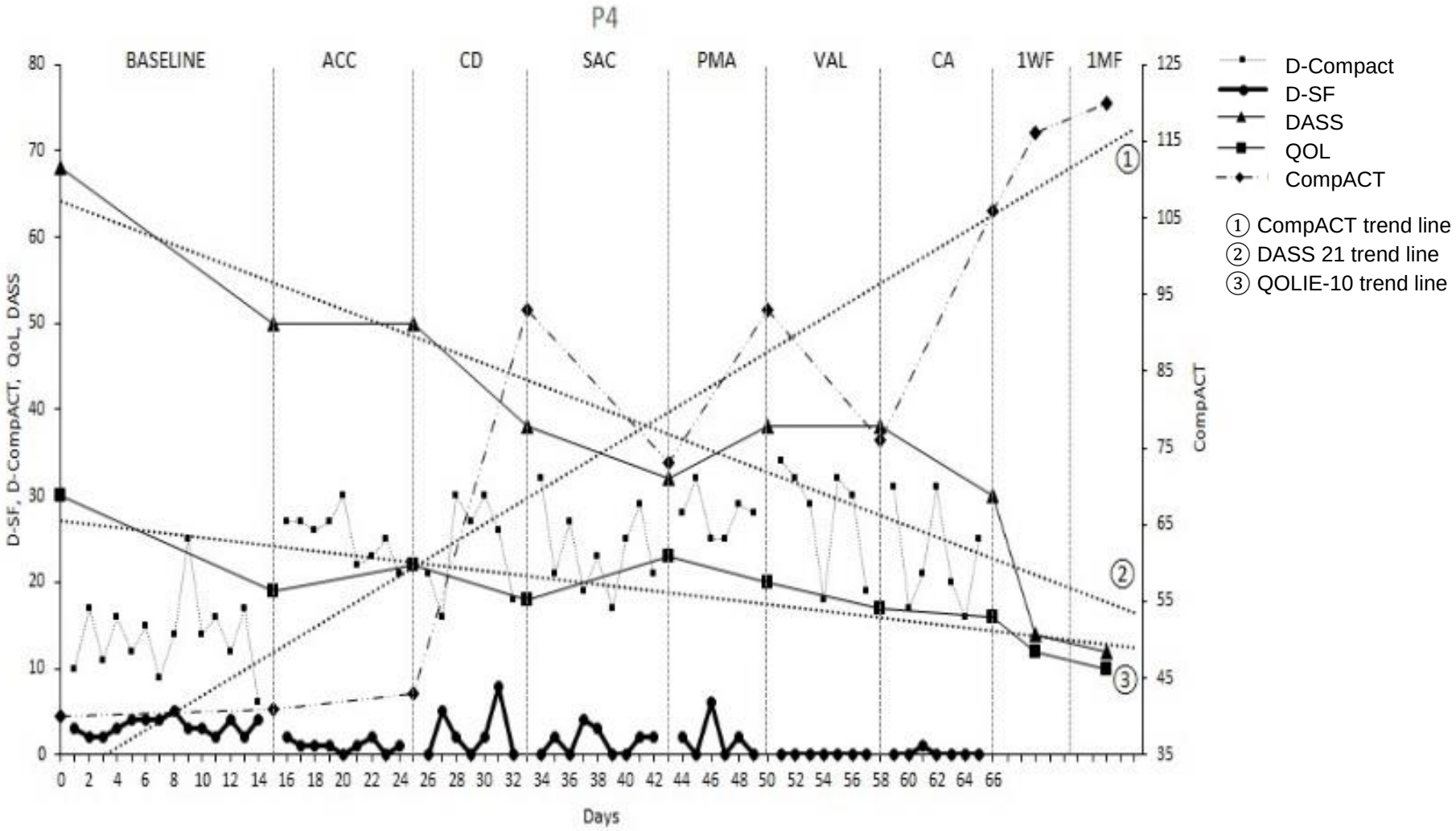


Figure 11. Time series data for Participant 4

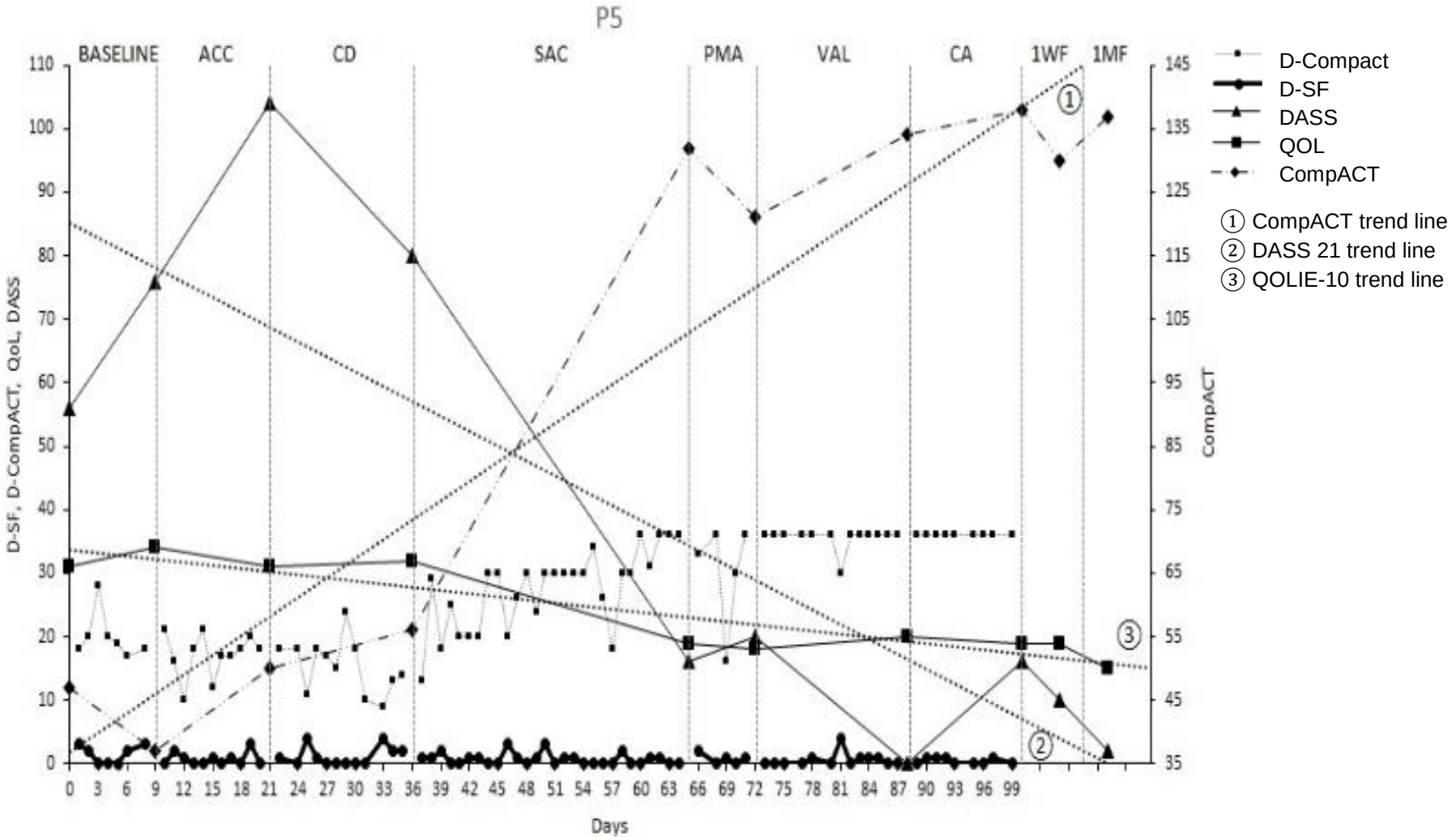
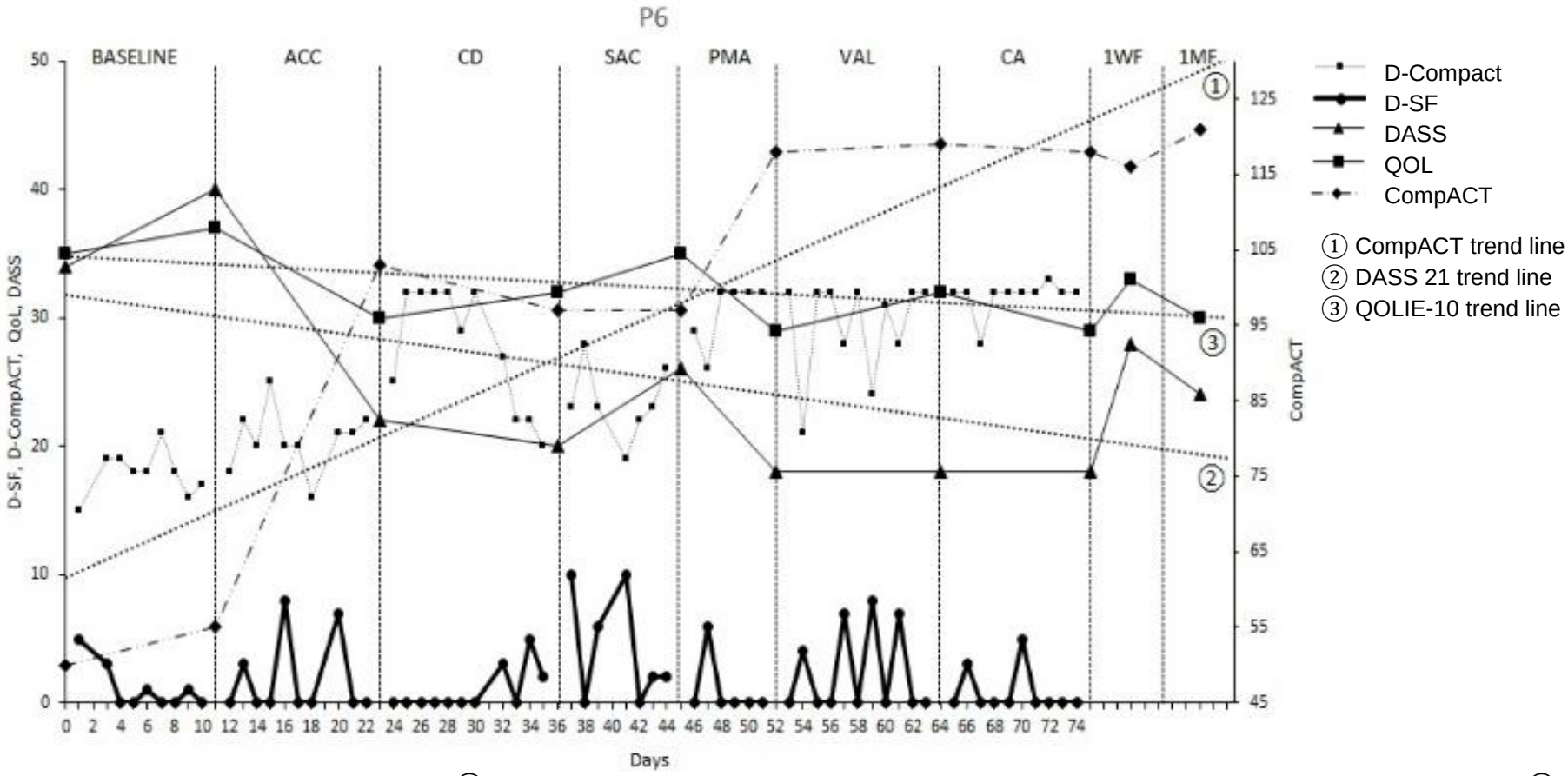


Figure 12. Time series data for Participant 5



Notes: An upward trend line on the CompACT ① indicates an improvement in psychological flexibility whereas a downward trend line on the DASS 21 ② and QOLIE-10 ③ indicates improvement in psychological distress and quality of life, respectively; D-CompACT=daily CompACT; D-SF=daily seizure frequency; DASS=Depression, anxiety & stress scale 21; QOLIE 10=quality of life; Acc=acceptance; CD=cognitive defusion; SAC=self as context; PMA=present moment awareness; VAL=values; CA=committed action; 1WF=1 week follow-up; 1MF=1 month follow-up.

Figure 13. Time series data for Participant 6

3.6. **Seizure frequency**

A reduction in seizure frequency was noted for all participants throughout the lifetime of the study, however at follow-up, P1 and P3 appeared to have an increase in their seizure frequency when compared with their pre and post scores. P2 showed a decrease in seizure frequency from pre to follow-up, and P4, P5 and P6 reported no seizures in the past week at one-month follow-up (see
Figure 14).

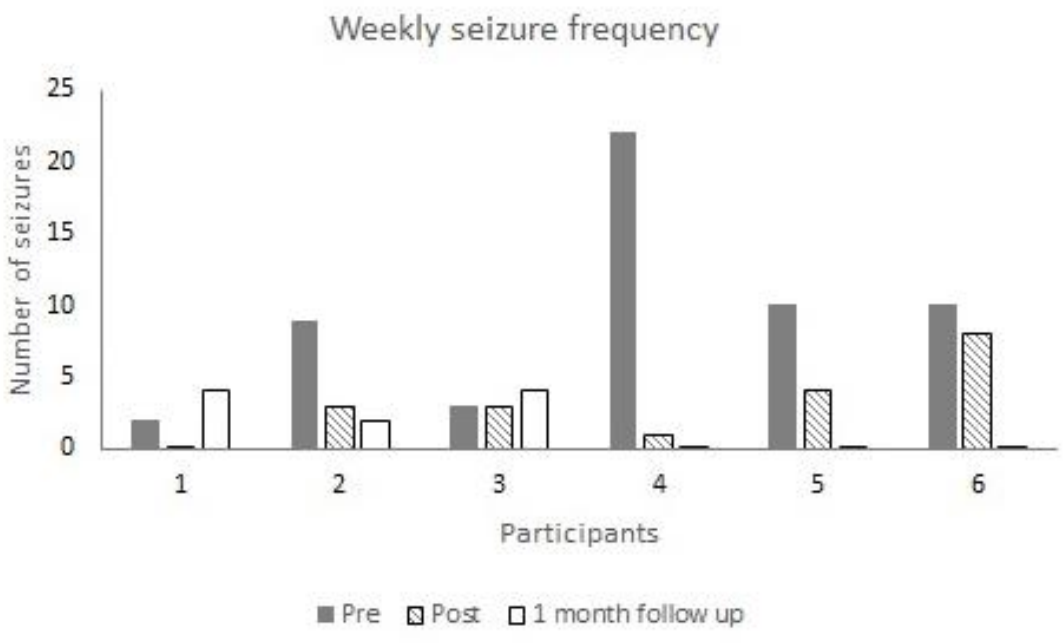


Figure 14. Pre, post and one-month follow-up weekly seizure frequencies

3.7. **Qualitative/Change interview results**

All participants took part in the change interview at one-month follow-up. The responses are illustrated in Table 7. (See Appendix F for the full interview schedule).

Table 7. Participant's responses to Change Interview questions

Ptp	Understand-able	Reco-mend to others	Influential chapter(s)	Overall Changes	Changes specific to seizures	Surprised by changes	Attribute to work book	Import-ance of changes	Most important area of life		Ext event	Therapist support
									Pre-	Now		
P1	No – chapters were sent out in batches	Yes	Committed action/ Values	Less avoidant	No	Neutral	Highly likely	Important	Mental function	Mental function	Yes – possible FND	Helpful
P2	Yes	Yes	Mindfulness	Coping skills Built confidence	Yes - attitude	Quite surprised	Neutral	Very important	Daily activities	Mental function	Yes – operation	Helpful & supportive
P3	Yes	Yes	Acceptance/ Mindfulness Cognitive defusion	More aware of thoughts Generally feeling better	No	Quite surprised	Highly likely	Very important	Daily activities	QOL	Yes-menopau-se/ familial illness	Helpful & supportive
P4	Yes	Yes	Role of language Mindfulness Values	"actively engaged in the present moment"	Yes – less of them	Neutral to quite surprised	Highly likely	Very important	Mood	QOL	No	Helpful & supportive
P5	Not at first – language was difficult	Yes	Mindfulness	More accepting	Yes – less of them	Very surprised	Highly likely	Very important	Mental function	QOL	No	Helpful & supportive
P6	Yes	Yes	Cognitive defusion	More accepting, feel free	No but less bothered by them	Quite surprised	Likely	Very important	Daily activities	QOL	No	Helpful

Notes: An independent researcher conducted the change interviews with each participant via telephone and structured the interview based on the interview schedule displayed in Appendix F.
Ptp=participant; Ext= influential external events during the study; QOL= quality of life; FND=functional neurological disorder

The results of the change interview indicated that most participants found the workbook easy to understand; P1 found the workbook less understandable due to the way in which chapters were sent out and distributed, whereas P5 found the language difficult to grasp when initially reading the workbook. All participants said that they would recommend the book to others and two thirds described the mindfulness chapters the most influential. All participants reported general changes throughout the study, such as feeling more accepting and mindful (P3, P4, P5 and P6), less avoidant (P1) and more confident (P2). In relation to changes specific to seizures themselves, two thirds of participants reported either having less seizures or feeling differently towards them and two participants reported no changes to their seizures. All participants attributed changes to the intervention and reported that these changes were important to them. Three participants indicated that there were external events that may have impacted on the outcome of the study such as having an operation (P2), experiencing menopausal symptoms and family illness (P3) and P1 reported that he felt he fitted the diagnosis of functional neurological disorder (FND) rather than PNES, which gave him hope whilst completing the study. Furthermore, all participants found the researcher support useful.

During the screening process and at the time of the change interview, participants were asked to indicate the areas related to their seizures that were most important to them at the time; for one participant, this domain remained the same at screening and at change interview, however, all other participants reported a change in this area. One participant reported that following the study, the most important domain was mental function, whereas the remaining participants reported that overall quality of life was now the most important domain for them.

[See Extended paper 3.5 for a results summary for each participant

4. Discussion

This study investigated *(i)* whether specific ACT processes related to PNES phenomena and *(ii)* whether a guided self-help ACT intervention impacted on PNES phenomena as a whole, including seizure frequency.

For most participants, the largest improvements in quality of life and psychological distress scores were observed after the processes of openness to experience (acceptance and cognitive defusion chapters). One participant displayed the greatest improvement in psychological distress and quality of life following the self as context phase, however, self as context and acceptance/cognitive defusion processes are highly related to one another [77], which may account for the findings here. Furthermore, although seizure frequency was not a primary outcome of the current study, more than half the sample reported a reduction in seizure frequency at post-intervention and at follow-up; suggesting that valued action processes (the last process chapters to be completed) may be an important contributing factor in behaviour change for individuals with PNES.

An increase is psychological flexibility was observed for all participants by the end of the intervention, though these changes were only clinically significant and reliable for four participants. While an increase in psychological flexibility was observed for the other two participants, their pre-treatment scores were already above the cut-off for clinical significance and therefore any changes observed could not be considered reliable. Clinically significant changes in psychological flexibility were observed at both one-week follow-up and at one-month follow-up for all participants whose initial pre-treatment scores fell below the clinical cut-off, suggesting that an ACT intervention had a significant impact on increasing psychological flexibility in the longer term. Furthermore, the ACT intervention was related to the long-term improvements found in psychological distress, quality of life and seizure frequency for participants at follow-up. Participants that did not achieve reliable or clinically significant changes in psychological flexibility showed no changes in quality of life, psychological distress or seizure frequency; indicating that improvements in all ACT

processes are important in delivering clinically meaningful and reliable change. As such, the findings of the current study provide further evidence that increases in psychological flexibility lead to improvements in psychological distress and meaningful functioning [49].

Experiential avoidance has been acknowledged as a possible underlying factor in the maintenance of PNES within the extant literature, with PNES populations often displaying high levels of avoidance [20,21,63,89]. Previous CBT studies that have utilised exposure techniques to help reduce avoidance in individuals with PNES have been somewhat successful, providing further support that avoidance is a key maintaining factor in PNES [42,44]. Whether the use of exposure techniques *per se* are directly attributable to the positive outcomes reported in Goldstein et al.'s [42,44] CBT studies is less clear, given the lack of information regarding the possible mediators of change in those cases. The current study provides evidence from both the quantitative analysis and qualitative change interviews that specific ACT processes of acceptance and cognitive defusion may be directly attributable to changes in experiential avoidance.

Participants that displayed high levels of experiential avoidance and cognitive fusion prior to starting the current study (as measured by the CompACT) showed the largest change in their psychological distress and quality of life scores following completion of the ACT process chapters aimed at targeting these areas (i.e. acceptance and cognitive defusion). The findings from the current study are consistent with the findings of Baslet and Hill [63], who conducted an "ACT" intervention with an individual with PNES, where mindfulness and acceptance techniques appeared to result in positive outcomes. As such, the role of acceptance and cognitive defusion strategies appears influential in increasing psychological flexibility, conceptualised as the 'inverse' of experiential avoidance, in individuals with PNES; measures of psychological flexibility increased, experiential avoidance decreased and experimental outcomes improved which was further supported by confirmatory evidence from change interviews. As such, future treatment protocols may benefit from incorporating these processes into their intervention plans.

Overall, the ACT self-help intervention appeared effective in producing positive outcomes in psychological flexibility, quality of life, psychological distress and seizure frequency for the majority of participants. Furthermore, improvements in psychological flexibility and seizure frequency were clearly replicated across four participants and improvements relating to quality of life and psychological distress were replicated across three participants. The replication of the intervention effect was observed across participants and therefore met SCED evidence standards criteria [90]; as such, evidence acquired from the present study supports the use of an ACT guided self-help intervention for a PNES population.

[See Extended paper 4.1 for a discussion of P1 and P3 where clinically significant changes were not observed]

[See Extended paper 4.2 for further discussion of findings in the context of extant research and theory].

4.1. **Strengths and Limitations**

The multiple baseline design used in the current study strengthens the inferences made about the treatment effect as all participants had stable or declining baselines on the daily psychological flexibility (D-CompACT) measure. In addition, as no participants began the intervention at the same time, internal validity was not threatened by history effects or maturation [91]. Nevertheless, the scores for daily psychological flexibility should be interpreted with caution as the D-CompACT was not subject to rigorous testing, bringing the measure's reliability and validity into question.

A further strength of the current study was the use of a SCED within a highly heterogeneous population, such as PNES [6,20]. Due to the difficulties in generalising findings across heterogeneous populations using nomothetic (group mean) designs [92], a SCED overcomes such limitations by accounting

for individual differences. However, there were difficulties interpreting the time series data in relation to how long it would take for a process to come into effect after having been read about, for example, improvements observed during one phase of the study (e.g. cognitive defusion) could be the result of carryover effects from the previous phase (e.g. acceptance) [91,93]. Although carryover effects are related to lasting effects of treatment, they limit the inferences that can be made about the effects of the intervention, therefore, obtaining participant feedback about the intervention was important in attempting to overcome these limitations. Conversely, the structures set out to strengthen the scientific rigor of the study (multiple outcomes data, weekly telephone contact, specific workbook sections and change interviews) also give a varied representation of the results (a recognised factor of SCED research; [94]), making it difficult to determine whether therapeutic changes were a result of the specific intervention process or other, non-specific factors, such as the relationship between participant and researcher, the cumulative effect of receiving chapters or the Hawthorne effect.

The collection of qualitative data (change interviews) interpreted alongside quantitative time-series data was a relative strength of the study, given the apparent convergence between the two for the majority of participants (regarding change identified from the time-series data and participants' perception of change). In addition, information from the change interview revealed that participants found the ACT workbook helpful and felt changes were a result of the intervention. Participants also identified these changes as important to them, suggesting that an ACT intervention is both acceptable and appropriate for individuals with PNES.

Additionally, although two thirds of participants reported reliable and clinically significant change in psychological flexibility (resulting in improvements in quality of life, psychological distress and seizure frequency), two participants did not; although an increase in their psychological flexibility scores was observed. The disparity in outcomes observed between participants makes the influence of ACT processes on PNES phenomenon less clear, however, the maintained positive outcomes at follow-up (for those who did achieve reliable and clinically significant change on a range of outcomes) supports the notion that an ACT

approach delivers long term clinically meaningful gains. Still, other factors such as the therapeutic relationship should not be dismissed in explaining changes in psychological flexibility in the absence of any behavioural changes.
[See Extended paper 4.2 for further discussion on strengths and limitations of the study]

4.2. **Clinical relevance**

The National Health Service (NHS) has a strategic vision to integrate physical and mental health services within the next five years as current services do not provide equity of access to psychological therapies for populations with long term and debilitating physical health conditions [95,96]. The use of guided self-help interventions is supported in providing greater access to psychological therapies [68,70,71] and benefitting patients that are often marginalised and possibly less likely or able to attend traditional psychological therapies [6,69,97]. The current study fits within the NHS strategic vision through enabling better access to psychological therapy for marginalised groups (such as PNES) in such a way that addresses the engagement limitations of that group whilst reducing frequent unwarranted visits to physical health services [98] and therefore, costs [12,99].

[See Extended paper 4.3 for a further discussion of the clinical implications of these findings].

4.3. **Conclusions**

The current study investigated the effects of a self-help ACT intervention for individuals with PNES, using a non-concurrent, multiple baseline design. The findings support the use of a guided self-help ACT intervention for treating people with PNES. Given some of the difficulties in treating people with PNES within formal 1:1 sessions [52,67], a self-help intervention may provide an alternative treatment approach for individuals experiencing PNES and has the potential benefits of widening access to therapeutic interventions [100]. Thus,

the current study provides detailed feasibility, acceptability and process data on how ACT self-help might work on a larger scale in keeping with the NHS's strategic vision [95].

The results of the current study indicate that for some individuals the ACT guided self-help intervention was not as effective in producing positive outcome data; however, this supports the idea that individuals with PNES fall into different subgroups [18] and therefore may require a different approach to intervention, for example, an ACT approach delivered within a more formal clinical setting.

4.4. **Future research recommendations**

The current research offers some support for the use of an ACT guided self-help intervention for individuals with PNES, however, the study's findings could be further supported by:

- Longer term follow-up to examine treatment effects after six and twelve months.
- Examining the differences between participants that showed changes in outcomes and those that did not; there may be further explanation as why changes were observed in certain participants and not others which may be a targeted area for future intervention studies.
- A larger scale study examining the effects of an ACT intervention compared with a CBT intervention; this would investigate whether either approach is superior in treating PNES or whether outcomes are a result of any treatment being better than no treatment.

[See Extended paper 4.4 for a discussion on future research recommendations]

Word count: 7,219

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1 Extended Background

1.1 Epidemiology and Impact of Psychogenic Non-Epileptic Seizures

1.1.1 Historical context

In ancient Greek times, hysteria was a common diagnosis given to women with unexplained symptoms, including seizure-like symptoms (Trimble, 2010). "Hysteria" was thought to be the result of a 'wandering womb' travelling through the body in search of semen, causing pressure in various places or "eating" parts of the brain as a substitute for semen, resulting in fever, sweating and screaming (Israël, 1983).

There has been a shift in the conception of psychogenic non-epileptic seizures (PNES) as time has evolved; the development of current thoughts about the psychological nature of PNES transformed in the early 1900s, when "hysteria" was also observed in men. At the time (early 1900s), a distinct psychological profile of "hysteria" in men was given, which was characterised by more aggressive tendencies. However, it was the work of Sigmund Freud that hypothesised that hysterical symptoms were related to traumatic memories in the unconscious. This brought about further investigation to the epidemiology of PNES and theories regarding emotions, personality profiles and trauma histories evolved.

The words used to describe PNES have also changed somewhat in recent years, with more pejorative terms such as 'pseudo-seizures' being replaced by terms that are more descriptive of the condition, such as psychogenic non-epileptic seizures or non-epileptic attacks, instead.

1.1.2 Recognition and diagnosis

Initial diagnosis of PNES is estimated to be more than 5/100,000 per year (Duncan, Razvi, & Mulhern, 2011) and approximately 20%-30% of patients who attend epilepsy centres with suspected refractory epilepsy are diagnosed with PNES (Angus-Leppan, 2008; Benbadis, Allen, & Hauser, 2000; R. J. Brown,

Syed, Benbadis, LaFrance Jr., & Reuber, 2011; N. M. Griffith & Szaflarski, 2010). PNES is normally diagnosed in early adulthood, however, there have been cases where individuals as young as 5 years old have been diagnosed with the condition (Reuber, Fernandez, Bauer, Helmstaedter, & Elger, 2002). Furthermore, PNES appears more prevalent in females and they are 3 to 4 times more likely to be affected than men (an estimated 75%-80% of people with PNES are female) (Benbadis et al., 2000; Bodde et al., 2009; Schmitz, 2010).

Due to the paroxysmal similarities between epilepsy and PNES, PNES is often misdiagnosed as epilepsy, resulting in inappropriate treatment and delays in receiving a correct diagnosis; Reuber et al. (2002) suggested that the average wait in receiving a correct diagnosis of PNES is seven years. The 'gold standard' in diagnosing PNES is through video-electroencephalography (V-EEG) (Kuyk, Leijten, Meinardi, Spinhoven, & Van Dyck, 1997; Mostacci et al., 2011); which has also been beneficial in the differential diagnosis of PNES and epilepsy (see section 1.1.3).

The classification of PNES can fall within several categories; most individuals fall within the DSM-5 category of Functional Neurological Symptom (conversion) disorder (American Psychiatric Association, 2013), whereas others may be categorised as having somatic symptom disorder, dissociative disorder, or post-traumatic stress disorder. The DSM categories mentioned above all consider PNES as an involuntary action although there have been reports of 'willed action' PNES or malingering; in such cases these would not necessitate a mental health diagnosis. The focus in the current study was of those who have involuntary actions.

1.1.3 Differential Diagnosis

Reported prevalence rates of comorbid PNES and epilepsy (ES) varies considerably, ranging between 5% and 50% (Benbadis, Agrawal, & Tatum, 2001; Szaflarski, Ficker, Cahill, & Privitera, 2000; Widdess-Walsh, Nadkiarni, & Devinsky, 2010). Diagnostic rigor (such as history taking, direct observation of events, video electroencephalogram (VEEG) monitoring) is largely attributable

for the marked variability in prevalence rates of PNES and ES. Although VEEG is the gold standard for obtaining a confirmed diagnosis of PNES, this is sometimes difficult to obtain due to: i) being able to video record seizures in real time; ii) the availability of testing; and iii) how vigilant professionals are in recognising PNES features and appropriately referring patients on for VEEG (Harden, Burgut, & Kanner, 2003). Furthermore, in patients with both ES and PNES, diagnosis of PNES is often delayed and patients being treated for 'suspected' epilepsy may present with a "pseudo response" to antiepileptic drugs (AEDs) where the epilepsy may be well controlled, but (psychogenic non-epileptic) seizures still continue; in these situations progressive escalation in the dosage of AEDs may occur, where the side effects of AEDs can have serious negative consequences when used for the treatment of PNES (LaFrance Jr. & Benbadis, 2006). Differential diagnosis of PNES in patients that also have ES is therefore important to both avoid the negative side effects of AEDs and to quicken access to more appropriate treatment.

1.1.4 Impact of PNES

Several studies have shown that high levels of depression are associated with PNES, with over a third of patients reporting self-harm and suicidal ideation and some patients reporting previous suicide attempts (Duncan et al., 2011; Ettinger, Devinsky, Weisbrot, Ramakrishna, & Goyal, 1999). Further studies have found that PNES is associated with other psychopathological conditions, such as anxiety, post-traumatic stress disorder, medically unexplained symptoms (MUS) and somatisation (Bodde et al., 2009; Dimaro et al., 2014; Duncan et al., 2011; Selkirk, Duncan, Oto, & Pelosi, 2008). Whilst a causal relationship between these psychopathological conditions and PNES has not yet been established, it is important to consider the impact of this association on individuals in terms of quality of life, functionality and psychosocial distress. For example, if one conceptualises that thoughts associated with anxiety influence behaviour, then thoughts associated with having a disability may influence behaviour in much the same way.

Patients with PNES report reduced quality of life, reduced functionality and high levels of psychosocial distress (LaFrance Jr. & Benbadis, 2006; Mercer, Martin, & Reuber, 2010; Szaflarski, et al., 2003b; Testa, Schefft, Szaflarski, Yeh, & Privitera, 2007), which may be related to patients not understanding the PNES diagnosis; some patients may be confused by the diagnosis and others may find it difficult to accept a psychological, rather than physical, explanation for their seizures (Carton, Thompson, & Duncan, 2003). Wyatt, Laraway and Weatherhead (2014) suggest that a diagnosis of PNES leads to negative self-perceptions in patients; they may think that they are “disabled”, “broken” and “unfixable” and the psychogenic nature of the seizures may mean that they perceive others to think “it’s all in [their] head” or they are “faking it”. These thoughts about themselves may be related to painful feelings and experiences and if patients behave in accordance with these beliefs of meaning it is possible that this would lead to reduced functionality, reduced quality of life and psychosocial distress (Denison, Asenlöf, & Lindberg, 2004).

Hamilton, Martin, Stone and Worley (2010) posit that the reduction in functionality often reported in PNES patients is related to avoidance and self-imposed restrictions on activity rather than physical disability. Relatedly, if avoidance and self-imposed restrictions are connected to views, expectations and beliefs about disability and functionality, then patients with PNES may have certain rules about what they can or can’t do; for example: “If I do X, Y or Z I will have a seizure, therefore I will not do X, Y or Z”. Avoidance strategies employed as a control tactic in this way may lead to further psychosocial distress and impaired functionality (Goldstein, Drew, Mellers, Mitchell-O’Malley, & Oakley, 2000)

Mercer et al (2010) also suggest that quality of life and functionality in PNES is closely linked to the underlying psychopathology of PNES rather than seizures themselves, supporting the idea that behaviour is influenced by a person’s relationship with their cognitions about having seizures. Therefore, treatments that focus solely on seizure control may not be sufficient if they do not also address the psychosocial factors that underpin the condition.

1.2 Theoretical approaches and models of PNES

1.2.1 Psychodynamic account

Psychodynamic theory suggests that personality is made up of the id, ego and superego. The id is a primitive, unconscious drive which constantly struggles for gratification (termed the 'pleasure principle'). The ego (coined the 'reality principle') is the present aspect of personality which mediates the drives of the id and superego. The superego is internalised moral agency, passed down from our parents and is capable of making the ego feel anxious and guilty (Freud, 1920). A key premise of psychodynamic theory is the role of repression; repression is thought to occur when thoughts or memories are too painful to have in conscious awareness, therefore these painful memories and thoughts are repressed into the unconscious (Fairbairn, 1943). However, at times of psychological crisis where the balance between the principles is disturbed, repressed content may find an outlet; it is important to note that the repressed content being "leaked" may be disguised as something else, as the ego attempts to further protect the individual from conscious awareness of the repressed material, therefore the content is expressed without feelings of guilt or anxiety (which would usually be imposed by the superego). In the case of PNES, the "leakage" may be seen in the form of seizures (Singer, 1995). In other words, the unconscious conflict is expressed as a symbolic symptom that is released without guilt; this keeps the psychological pressure between the principles within manageable limits, and therefore the painful content continues to be repressed. Furthermore, apart from psychological pressure being released in the form of seizures (primary gain), symptoms may function to obtain care from others or avoid certain responsibilities (secondary gain). See Figure 15 for a diagram of the process involved for PNES.

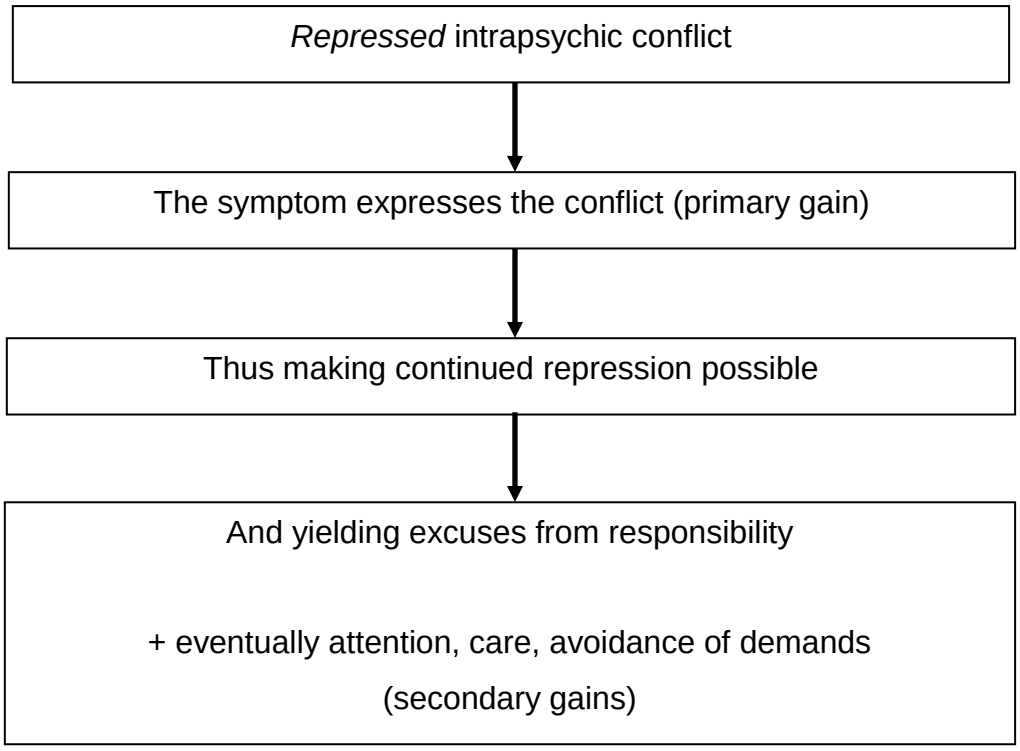


Figure 15. A Psychodynamic model of PNES taken from LaFrance Jr. and Bjørnæs (pg. 267, 2010)

Psychodynamic theory appears to account for the psychological underpinnings of PNES, therefore, psychodynamic therapy approaches have previously been a widely accepted technique in treating the condition (Brooksbank, 1984; Goodwin, 1979), despite the lack of systematic outcome data for this approach (Kalogjera-Sackellares, 2004). Furthermore, other approaches with larger evidence bases may offer alternative frameworks in which to understand and treat PNES.

1.2.1.1 *Psychodynamic treatment*

Howlett and Reuber (2009) described a psychodynamic treatment approach for PNES, which was adapted from psychodynamic treatment models for functional somatic disorders (Creed et al., 2003; Guthrie, Creed, Dawson, & Tomenson, 1991). Treatment focused on forming an explicit link between the patient's symptoms and their problems in interpersonal relationships and consisted of

helping the patient develop an awareness of their feelings, make connections between feelings both inside and outside of therapy, and understand unhelpful repeated patterns of behaviour as underlying reasons for their difficulties. Furthermore, psychodynamic models combined with somatic traumatic therapy may be helpful when using with a patient with PNES, given the symptomatology and psychological trauma often apparent in within this population (Clements, 2003).

1.2.2 Behavioural account

1.2.2.1 *Classical Conditioning*

Classical conditioning assumes that certain stimuli (UCS) elicit a certain response (UCR) out of necessity, which is often 'hard-wired' rather than learnt. Classical conditioning occurs when another neutral object (NS), that has not elicited a response, is associated with the previously unconditioned response. In this way, the neutral object has been conditioned (CS) to give a certain response (CR) (see
Figure 16).

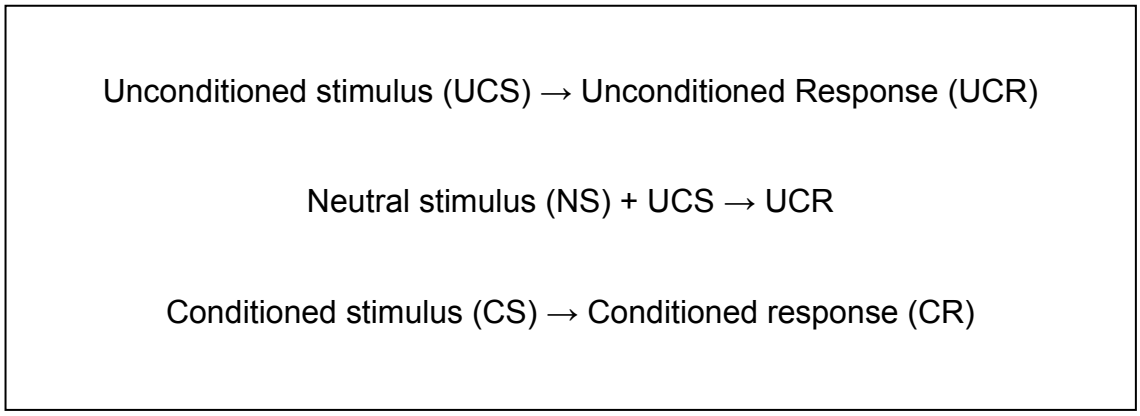


Figure 16 Classical conditioning model

In terms of applying the classical conditioning model to PNES, one might propose that a patient with epilepsy whose epileptic seizures appear to be repeatedly elicited by flickering lights in the kitchen; therefore, objects that were

initially neutral, for example, a microwave, might eventually elicit similar (though not identical) seizures, with the difference being a lack of epileptiform EEG correlates (LaFrance Jr. & Bjørnæs, 2010). This conditioned response may generalise so that in the future the sight of a microwave may elicit non-epileptic seizures (see
Figure 17).

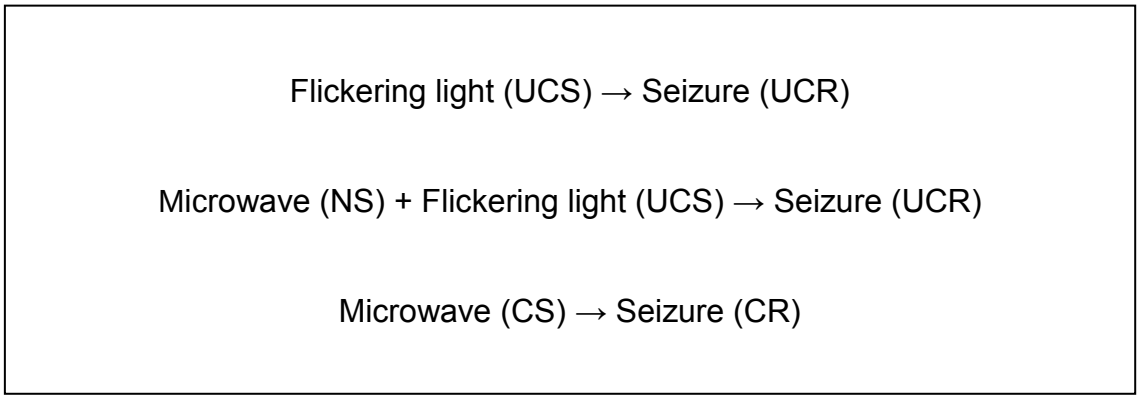
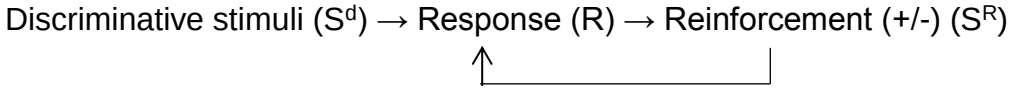


Figure 17 A Classical Conditioning model for PNES

1.2.2.2 *Operant conditioning*

An operant conditioning model assumes that behaviours are acquired through the contingencies that follow it (e.g. reinforcement/punishment); reinforcement may be positive, that is, behaviour is reinforced by pleasurable or pleasing consequences, or behaviour may be reinforced (negatively) by the avoidance of negative or aversive consequences. Responses (behaviour) do not need to be related to previously known stimuli, although there may be some relationships where stimuli are acquired before conditioning (called “discriminative stimuli”) which might influence the operant behaviour:



In operant conditioning, the notion of shaping (which refers to the reinforcement of the response being contingent upon successively more frequent responses)

explains how initially a small response (such as small non-epileptic seizures) can develop into intense and uncontrollable responses (such as debilitating non-epileptic seizures).

Operant conditioning principles have been shown in the chronic pain research; Sullivan, Adams and Sullivan (2004) found that behaviours in chronic pain patients (such as complaining of pain and pain behaviour) were reinforced by the presence of others. Furthermore, classical and operant conditioning paradigms have been used together to develop a fear-avoidance model of pain that could also provide a useful framework for explaining the maintenance of PNES (Linton, Melin, & Gotestam, 1984) (see Figure 18). Using this framework, we can see how a threatening situation (S^d/CS) might precipitate a seizure (R); a conditioned response of sympathetic activation and anxiety is elicited (CR), which leads to the avoidance of the situation (R). As such, the behaviour is reinforced via avoidance of the aversive stimuli (S^R).

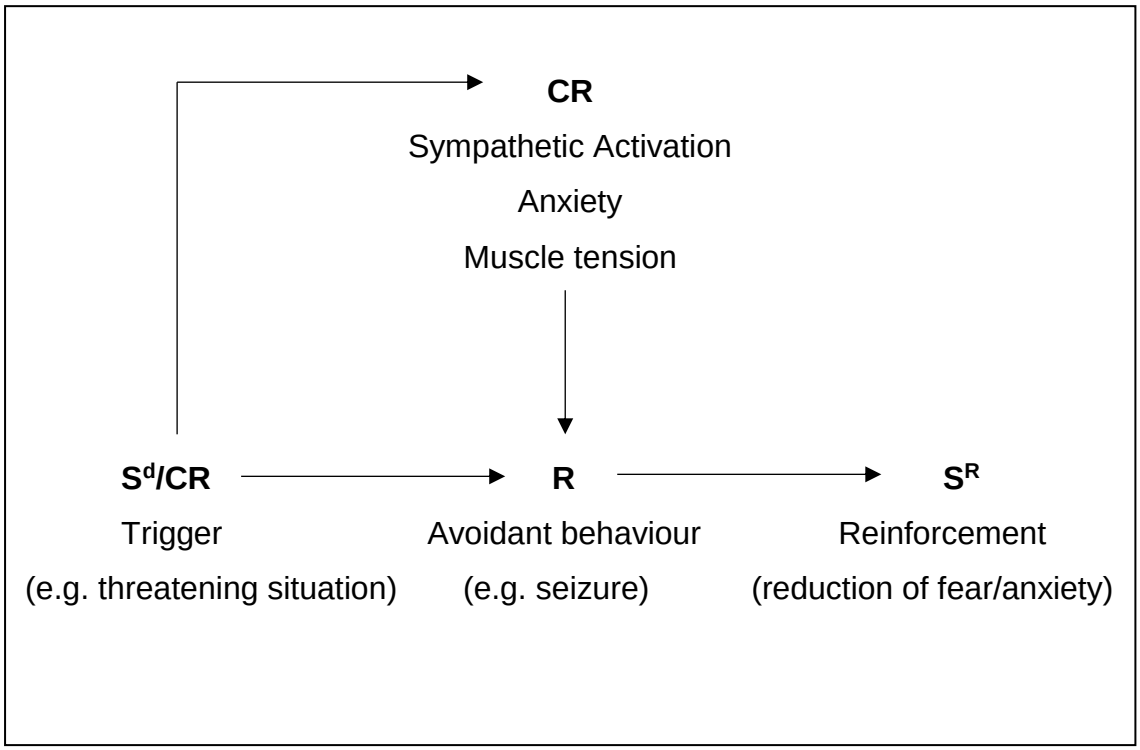


Figure 18 Activity avoidance model of PNES, adapted from Linton et al. (1984)

The utility of the above model is supported by Goldstein and Mellers (2006), who found that patients with PNES were more likely than their epilepsy counterparts to identify more anxiety symptoms and avoidance behaviours. Furthermore, studies examining behavioural treatments show that behavioural approaches incorporating functional analysis and operant conditioning processes are helpful in reducing and preventing seizure behaviour (Dahl, Melin, & Leissner, 1988; Sterman, 2000).

Behavioural approaches are helpful insofar as they appear to explain to some extent how seizure behaviour can be prevented or reduced, however, they may not account for thought processes involved or the underlying psychopathology of the condition, whereas the psychodynamic approach offers more understanding in that area. However, behavioural approaches allow for systematic testing when compared with psychodynamic approaches. Furthermore, behavioural approaches are not dependent on knowing the person's history and focus on the present.

1.2.2.3 *Behavioural treatment*

Behavioural treatment for PNES focuses on operant conditioning and functional analysis processes. The use of positive reinforcement (to augment appropriate seizure free behaviour), punishment (to extinguish inappropriate seizure behaviour), and avoidance of negative reinforcement has received some support in its utility with conversion and other dissociative disorders (Aamir, Hamayon, & Sultan, 2011; Campo & Negrini, 2000; Shapiro & Teasell, 2004). Behavioural diaries can be used to aid functional analysis of seizure behaviour and this behavioural technique is often incorporated into other behavioural therapies, such as cognitive behavioural therapy (see next section) (LaFrance Jr. et al., 2009; LaFrance Jr., Reuber, & Goldstein, 2013).

1.2.3 Cognitive Behavioural account

Cognitive behavioural therapy (CBT) was originally developed for the treatment of anxiety and depressive disorders and is now applied to a whole spectrum of

disorders including somatoform disorders (including chronic fatigue syndrome, chronic pain and irritable bowel syndrome) (Deary, Chalder, & Sharpe, 2007; Henningsen, Zipfel, & Herzog, 2007). Patients with PNES share a number of features of those with somatoform disorders, such as holding strong physical attributions and the avoidance of activities (Goldstein & Mellers, 2006; Stone, Binzer, & Sharpe, 2015) as well as experiencing considerable distress. The CBT models described for treating somatoform disorders include general cognitive behavioural approaches, such as the development of an individualised formulation, focusing on disrupting vicious cycles of maintaining factors; including avoidance, discussing the consequences of early childhood experiences, confronting unhelpful thoughts and considering symptom attribution (Deary et al., 2007). However, due to the complex features of PNES and the physical impact of seizures on the individual (including injury, impaired responsiveness and amnesia), there may be challenges in using a CBT approach for the treatment of PNES.

Goldstein and Mellers (2006) noted the similarities between the somatic symptoms of PNES and panic disorder, such as chest tightness, hyperventilation and palpitations. Furthermore, Goldstein and Mellers (2006) found that agoraphobic avoidant behaviour was three times more prevalent in patients with PNES than in those with localised epilepsy. Patients with PNES rarely report feelings of anxiety during their seizures, however, given the similarities of symptoms with that of panic disorder, Goldstein and Mellers (2006) suggested that PNES could be seen as a dissociative response to arousal, with avoidant behaviour acting as an important factor in maintaining seizures. In addition, Hixson, Balcer, Glosser and French (2006) found that patients with PNES also reported elevated levels of fear sensitivity (again, sharing similarities with a somatoform population; Vlaeyen & Linton, 2000), suggesting that PNES could be understood within a fear and avoidance framework.

A fear-avoidance model originally developed for musculoskeletal back pain by Vlaeyen, Kole-Snijders, Boeren and Van Eek (1995) can be adapted for PNES and may help explain the maintenance of non-epileptic seizures and associated

anxiety and avoidance (See Figure 19). Chalder (1996) demonstrated the efficacy of utilising this model for an individual with PNES using a single case design. The main treatment component was graded exposure to specific avoided stimuli; clinical improvements such as cessation in seizures and improvements in associated avoidances were found following treatment and at four-year follow-up.

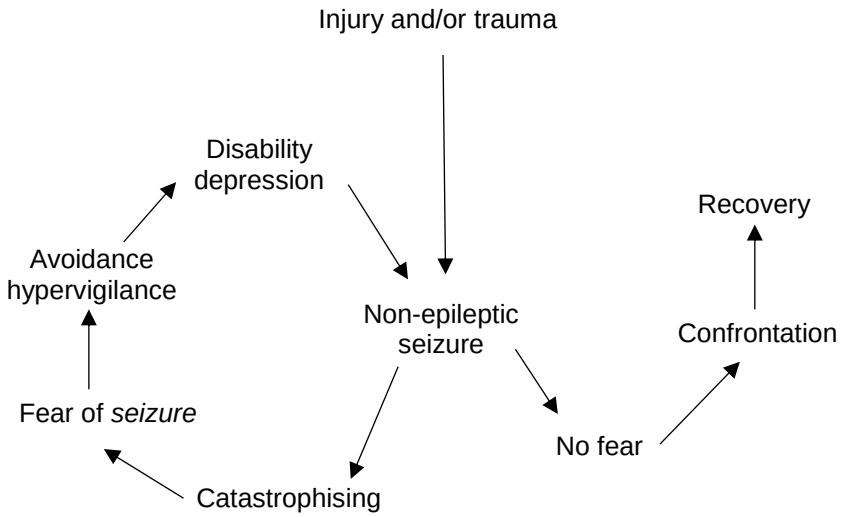


Figure 19. The fear-avoidance model (adapted from Vlaeyen et al., 1995)

Vlaeyen et al.'s (1995) model accounts for the interaction of cognitions, emotions, behaviours and physiology and provides a framework for understanding the maintenance of seizures, however, it does not account for seizure onset and is limited by this.

Other models that may account for seizure onset are typically the traditional Beckian CBT models, in which predisposing, precipitating and perpetuating factors are distinguished (Beck, Emery, & Greenberg, 1985). The strength of such a model in relation to PNES is that the generation of physical symptoms in the absence of physical pathology can be explained, making it distinct from other biological models of illness (Wade & Halligan, 2004). However, applying

such a model to PNES overlooks some of the physical and biological indicators often reported within the evidence base.

There are CBT models for somatoform disorders and medically unexplained symptoms that make use of predisposing, precipitating and perpetuating factors (Hutton, 2005; Reuber & Elger, 2003; R. D. Richardson & Engel, 2004), which hypothesise that perpetuating cognitions, behaviours and physiological responses are precipitated by an 'event'. In relation to PNES, several researchers suggest that seizures are thought to be precipitated by 'life events' (Bodde et al., 2009; Stone et al., 2015). Precipitating life events are thought to result in a long-term stress response, predisposed by a genetic or early experiences element, which over time may have neurological consequences. The examination of major stress systems (such as the hypothalamus–pituitary–adrenal axis) show that there is some evidence for the concept of a prolonged stress response in patients with PNES (Bakvis et al., 2010; Simeon et al., 2007), however, not all physiological responses to stress have been found in PNES (Müngen, Berilgen, & Arıkanoğlu, 2010).

A CBT model for medically unexplained symptoms which incorporates predisposing, precipitating and perpetuating factors has been described by Deary et al. (2007) and can be used as a framework for understanding PNES (see
Figure 20). According to this model, combined predisposing elements such as early adversity and innate personality factors lead to an increase in distress sensitivity and reduced distress tolerance. Furthermore, precipitating life events, stressors and viruses accompany predisposing factors which produce more symptoms (along with cognitive, behavioural, social and psychological factors). As a result of this development, a process of 'sensitisation and selective attention' is produced which leads to a decrease in symptom detection. Precipitating factors become associated with symptoms, whilst avoidance strategies are reinforced through operant conditioning, thus, a cycle is produced which maintains symptoms and distress.

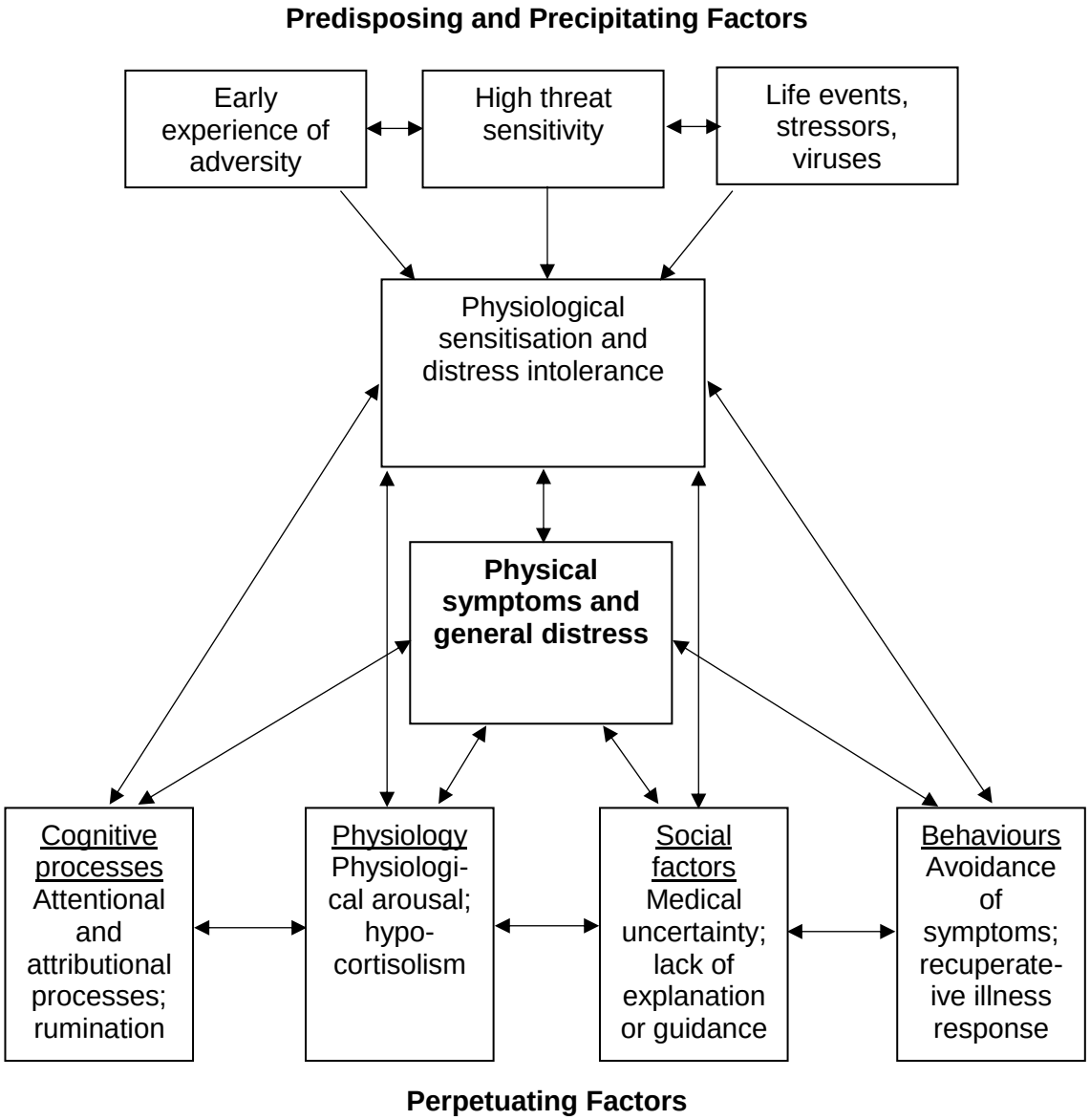


Figure 20. CBT model of medically unexplained symptoms (Deary et al., 2007)

Deary et al.'s (2007) model is more sophisticated than the earlier fear-avoidance model and accounts for possible predisposing and precipitating factors of in the development of PNES. In that sense, it is similar to Reuber's (2009) multi-factorial model (see Journal Paper Figure 1), however, from a treatment perspective, intervention is likely to focus on disrupting the

maintenance cycle, therefore, in terms of clinical applicability, this model is not considerably different to Vlaeyen et al.'s (1995) fear-avoidance model of PNES.

1.2.3.1 *Cognitive behavioural treatment*

CBT treatment for PNES combines the elements of both behavioural and cognitive therapies. CBT treatments based on Chalder's (1996) fear escape-avoidance model (the assumption that an inability to tolerate warning signs of severe distress leads to a conditioned response of PNES or avoidance/safety behaviours to prevent occurrence of PNES) employ graded exposure to arousal-provoking situations. In order for patients to manage the exposure protocol, they were initially taught responses that helped them manage dissociative cues, such as relaxation, distraction and refocusing techniques (Dahl et al., 1988; Dahl, Melin, & Lund, 1987).

The cognitive aspects of CBT treatment for PNES focus on seizure related thoughts, which are likely to occur more frequently when patients are exposed to feared situations. The techniques employed to challenge unhelpful seizure related thoughts include the identification of thinking errors (i.e. catastrophising and dichotomous thinking) (Rief, Hiller, & Margraf, 1998) and the development of alternative appraisals to thoughts (Goldstein, LaFrance Jr., Chigwedere, Mellers, & Chalder, 2010; Mellers, 2005).

1.2.4 Systemic account

A conceptual framework of somatoform disorders was developed by Minuchin and his colleagues when initially working with families of children with psychosomatic symptoms (Minuchin, 1974; Minuchin & Baker, 1978). Certain “transactional” patterns of interactions were noted within these particular families, such as enmeshment (intense family interactions), rigidity (extreme conformity to family rules), overprotectiveness and a lack of willingness or ability to engage in conflict resolution. The authors noted that the family usually presented itself as happy and successful, apart from the existence of a problem: psychosomatic symptoms in one member of the family (Minuchin et al., 1975).

Within this framework, the “problem” (i.e. the symptom), is thought to be functional within the familial system: firstly, to express conflicts and personal needs in a way so that the child (patient) cannot be blamed, and secondly, to draw attention away from something else that the family do not want to confront. Relatedly, illness behaviour is reinforced by feedback loops; conflict is avoided and focus on the “problem” continues.

Although Minuchin and colleagues model was developed as a framework for understanding children with somatoform disorders (such as ‘brittle’ diabetes, psychosomatic asthma, and anorexia nervosa; Minuchin et al., 1975), the framework is also useful in conceptualising PNES. A few studies have examined the function of PNES within a familial context; Wood, McDaniel and Burchfiel (1998) found that tendencies to somaticise, family distress and family criticism may contribute to PNES. Similarly, other studies have found that people with PNES tended to perceive their families as less supportive and committed in comparison to people with epilepsy (Moore, Baker, McDade, Chadwick, & Brown, 1994), or perceived their families as dysfunctional with high levels of family conflict (Krawetz et al., 2001), however a cause and effect relationship was less clear.

1.2.4.1 *Systemic treatment*

Within a family systems model, change is thought to occur by challenging family communication and transactions. The therapist joins the family system and leads the therapeutic process as part of the system (Minuchin et al., 1975). The symptoms (seizures) and family problems are externalised, placing them in a context of social reality which the family must then face (J. L. Griffith, Polles, & Griffith, 1998; Seltzer, 1985).

1.2.5 Conclusions from the theoretical approaches

The above theoretical approaches of PNES all offer different accounts in further understanding the development of PNES and potential treatment according to the model-specific proposed mechanisms of PNES. However, there remains

limited to no explanation within each of the theories described above which account for the seizure-like behaviour in PNES; none of the theories provide any evidence for the behavioural manifestation of proposed underlying psychological mechanisms which appear as seizures. A gap in the literature remains in explaining seizure-like behaviour; symptom modelling theory (see Journal Paper 1.2) provides a limited explanation of the behavioural manifestation of PNES which can only be narrowly applied. Similarly, the model used within the current study (Acceptance and Commitment Therapy; ACT) does not provide an explanation for the behavioural manifestation of seizures. However, within the ACT approach (see next section) the manifestation of seizures is not considered important in treating the condition; ACT is concerned with the willingness to accept and open up to internal and external emotional and behavioural states meaning that understanding the behavioural manifestation of PNES is not a prerequisite to undergoing an ACT intervention nor necessary to explain its application to PNES.

1.3 Acceptance and Commitment Therapy

Acceptance and Commitment therapy (ACT) is underpinned by relational frame theory (RFT; Hayes, Barnes-Holmes, & Roche 2001); the following section describes RFT in more detail and how it has shaped ACT processes.

1.3.1 Relational Frame Theory

In RFT, relational frames are made up of networks of mutual relations which largely govern our behaviour. Relational frames are the core of human language and cognition and allow humans to learn without the need for direct experience. For example, a cow will not put its head against an electric fence more than once, however, it will have needed to do this initially to learn that it gives an unpleasant shock; a child will never need to touch an electric fence to know that it would give them a shock as they can be verbally taught this. Humans think relationally and have the ability to arbitrarily relate stimuli to other stimuli, whereas it appears that non-humans do not (Hayes et al., 2001).

Responses can be socially determined according to context (‘arbitrarily applicable’), for example, a child presented with pictures of the Prime Minister, a wrestler, and a homeless person and asked to “pick the biggest”, would likely choose the one that looked the biggest in size (probably the wrestler), however, an older child, when asked to pick the biggest, would likely choose the Prime Minister, as they would have related “bigger” with “more important” and made their choice using the relational frame after seeing a picture of the Prime Minister.

Relating as a learnt form of behaviour is thought to contain three main properties:

- Mutual entailment: if, within a particular context, A relates to B, then it is derived that there must also some form of relation between B and A (in that context). For example, if one learns that ‘wooded areas’ contain ‘snakes’, then one would also derive that ‘snakes’ are contained in ‘wooded areas’ (Blackledge, 2003)
- Combinatorial entailment: if, within a particular context, A relates to B, and B relates to C, then it is derived that there must be a form of mutual relation between A and C, in that context. For example, if Thomas is stronger than Dave, and Dave is stronger than Mark, then a derived mutual relation between Mark and Thomas would be entailed, in a given context (in this case, that Thomas is stronger than Mark).
- Transformation of stimulus functions: relating responses between stimuli leads to the transformation of stimulus functions for all related stimuli. For example, if a gambler who bet on fights attributed winning to the strength of the fighter (and a fight broke out between the three gentlemen named in the above example), then the gambler would bet on the strongest (Thomas) to win. However, if the gambler was told that Thomas didn’t use weapons and that Dave hated fighting, but that Mark uses an array of weapons and unlawful tactics in a fight, then the gambler who initially perceived strength as the main contributing factor in winning a fight, would then bet on the weaker of the three fighters (transformation of

stimulus function) to win the fight, without the need for direct learning experience.

The aforementioned properties combine to make up ‘relational frames’. Relational frames are thought to be the basis for all human thought, language and behaviour (Hayes et al., 2001)

1.3.2 RFT and Psychopathology

RFT is clinically relevant because the functions attributed to one member of relational events tend to alter the functions of other relational events. For example, if a child was taught the verbal word “dog” which related to the animal, then further relations would be derived (e.g. the written word “dog” and the verbal “dog”, and the animal to the written word “dog”). Then, if a dog barked aggressively at the child and the child ran away and cried, the child would also run away and cry another time upon hearing his father say, “Oh look, a dog”, even though the child was not barked at when he heard the words “Oh look, a dog”. This example can explain why people who feel panic when feeling “trapped” in a supermarket then also worry about being “trapped” in a car, in a relationship, or in a job (Hayes, 2004). As a result, relational frames have the capacity to cause psychological distress.

Relational networks allow humans to plan, make decisions, solve problems, create art, however, they can also cause distress. The processes involved in RFT often means that language has a narrowing effect on behaviour (e.g. rumination) and may lead to psychological inflexibility (the inability to change behaviour, even when it is distressing) as a result of experiential avoidance and cognitive fusion (Hayes, 2004).

1.3.3 Experiential avoidance

Experiential avoidance is the attempt to avoid painful private events, even when doing so causes psychological harm (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). Just having names for events causes remembrance and attributions, for example, the memory of the death of a loved one can be triggered by a myriad of relatedly derived events, such as a picture, a smell, a

sunset, which can trigger feelings of sadness and behaviours such as crying or withdrawing. An individual might attempt to avoid or supress painful thoughts and feelings, however, the action required to supress painful feelings will lead to cueing the avoided event, and therefore strengthen the relational frames (e.g. “don’t think about ‘x’” becomes a contextual cue for “x”) (Hayes, 2004).

1.3.4 Cognitive Fusion

If an individual is “fused” with their thoughts (e.g. believing thoughts are a true representation of reality rather than a normal cognitive process), then the individual will behave in accordance with the thoughts they have. For example, if an individual is fused with the thought, “I’ll ruin everything if I have a seizure in public”, then their behaviour will reflect this: they will not go out in public because they would ruin everything (Hayes et al., 2001, 1996).

1.4 Applicability of Acceptance and Commitment Therapy for Psychogenic non-epileptic seizures

When applied to PNES, the processes of experiential avoidance and cognitive fusion help explain how PNES phenomenology is maintained. For example, someone with PNES may have the thought: “my seizures ruin everything”, and fusing with this thought also augments the thought with other mutual relational frames, such as “I ruin everything”. As a likely result of this, when someone with PNES thinks about doing something they enjoy, or something they were once able to do, such as go to the cinema with friends, the thought about how their seizures ruin everything arises (another mutual relational frame). The individual may then attempt to avoid this thought or suppress it, however, in doing so from an ACT perspective, this actually enhances the fusion of the thought: the person may find that they are using so much effort to avoid and supress the thought, that they are not aware of or engaging in other meaningful activities that would be psychologically beneficial for them and they therefore experience more psychological distress.

In order to alleviate distress, the individual may engage in psychological (e.g. rumination/dissociation) or behavioural avoidance (avoid going to the cinema). Such emotional and situational avoidance may lower distress in the short term (as it is negatively reinforcing), however, it is likely that continual avoidance will lead to a reduction in the number of meaningful activities engaged in, which would logically result in reduced functionality and quality of life (Denison et al., 2004; Ruiz, 2012; Wyatt et al., 2014). Additionally, Gurr (2014) also suggested that the continued use of avoidance strategies can result in further psychological distress.

1.4.1 The six ACT processes in treating PNES

The goal of ACT is not to reduce symptoms, but to increase psychological flexibility; to encourage willingness and acceptance of the experience of distress, when doing so serves to move towards/behave in line with values. Various studies have already demonstrated how helpful ACT can be in reducing distress and symptomatology in medical health conditions, such as in chronic pain (Hann & McCracken, 2014; McCracken, Vowles, & Gauntlett-Gilbert, 2007; Robinson & Hayes, 1997; Wetherell et al., 2011), and epilepsy (Lundgren, Dahl, Melin, & Kies, 2006; Lundgren, Dahl, Yardi, & Melin, 2008). The reduction in emotional and behavioural outcomes of distress and symptomatology are thought to be 'secondary effects' of an ACT intervention, which occurs following a severance in the avoidance cycle (achieved through psychological flexibility). Such outcomes may also reflect the increased contact the individual now has with previously avoided painful thoughts and events.

ACT is a non-disorder specific model, therefore the processes involved in increasing psychological flexibility can be applied to any form of psychological distress, regardless of whether it is a clinical or non-clinical problem (Hayes & Smith, 2005). Psychological flexibility is increased through the six core processes of ACT (See
Figure 21), which aid exposure to previously avoided painful events/thoughts through acceptance and mindfulness strategies while working in value-based direction.

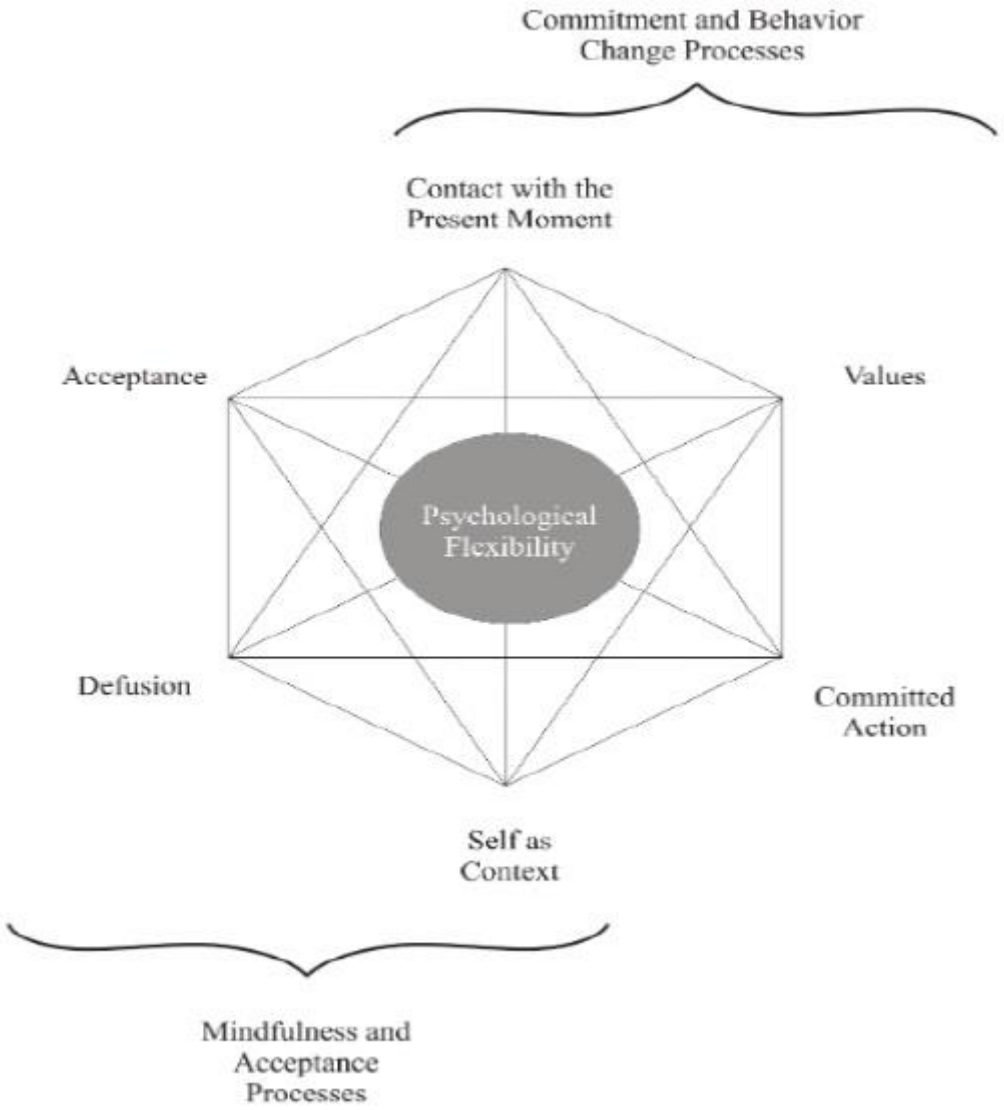


Figure 21. The six core ACT processes involved in increasing psychological flexibility (Hayes, Strosahl, & Wilson, 1999)

1.4.1.1 *Acceptance*

Acceptance is the opposite of experiential avoidance; fostering acceptance involves the purposeful awareness of distressing private events without attempting to change the frequency or form of such private events, especially when doing so causes psychological harm.

1.4.1.2 *Cognitive Defusion*

This involves altering the unhelpful function of private events; ACT attempts to change how clients relate to thoughts, rather than attempting to change the form, frequency, or situational sensitivity of the thought. Several techniques have been described to aid cognitive defusion, such as saying the thought over and over again until the words lose meaning, or being aware of the process involved in having a thought (i.e. “I ruin everything”, is the process of “I’m having the thought ‘I ruin everything’”). The result of defusion is the decreased believability or attachment to the avoided thoughts or private events.

1.4.1.3 *Self as context*

To aid acceptance and defusion, the client is encouraged to differentiate between the content of private events (such as thoughts, memories, feelings) and the contexts in which they occur; it is the ability to differentiate between ‘the thought’ and ‘the thinker’. Self as context is promoted through mindfulness, experiential processes and metaphors.

1.4.1.4 *Present moment awareness*

Non-judgemental contact with psychological and environmental events in the present moment is encouraged. The goal here is that clients are in contact with the present moment more fully, to enable higher flexibility in their behaviour which in turn relates to actions that are consistent with their values. Within this process, clients are taught to notice their surroundings, including bodily sensations and private events, without judgement and without the influence of past or present thoughts.

1.4.1.5 *Values*

In ACT, values are described as chosen qualities of ongoing action. Values describe what the client wants their life to stand for in a range of areas (family, career, spirituality etc.) which allows the client to then behave consistently in that chosen ‘life-direction’. The processes of acceptance, cognitive defusion and present moment awareness are not a means to an end in themselves; rather,

they help the individual identify what their values are and what currently obstructs their path (avoidance, fusion etc.) to a more meaningful, valued life.

1.4.1.6 *Committed Action*

Committed action is the development of effective action guided by values. Values-guided action likely raises a range of thoughts and feelings, sometimes uncomfortable and painful, therefore committed action means “doing what it takes” to live a valued consistent life and be willing to experience the pain and discomfort that arises as a result of this. All traditional behavioural interventions can be used within the ‘committed action’ component of the model, including goal setting, exposure and skills acquisition training, provided this is in the service of valued-consistent ends and not in the service of experiential avoidance.

1.4.2 Critique of ACT and its application to PNES

The main difference between ACT and other psychological approaches is that ACT does not attempt to alter the form of function of thoughts, unlike in CBT where a thought such as “my seizures ruining everything” may be subject to cognitive restructuring and reappraisals. From an RFT perspective, attempting to control thoughts in this way emphasises paradoxical behaviour, as relational frames will be activated by having thoughts about controlling thoughts, making it impossible to do so. It is also possible that, within ACT, further rule-governed behaviour develops as a result of relational frames, for example, a verbal rule such as “I should not fight the thoughts I have about how my seizures ruin everything” may develop. In this sense, it is almost impossible for any conversation to occur without activating relational frames, and within therapy, this is likely to occur, even if the way in which therapy is delivered is different to another, as the activation of relation frames is unavoidable. Paradoxically, resistance may result in attempting to develop acceptance and openness, due to the ubiquitous nature of relational frames, which would be damaging for the client.

Avoidance has been suggested as a core factor in the maintenance of PNES phenomena, therefore, despite the limitations of an ACT approach suggested

earlier, there may be some benefits in using an ACT model; openness to experience and behavioural awareness processes may increase the client's willingness to approach previously avoided stimuli (including private events) while valued action processes may provide increased motivation for the individual to be exposed to suppressed material. Avoidance has been linked with reduced functionality and therefore reduced quality of life in people with PNES, therefore if patients can be helped to live meaningful lives, despite seizures and associated psychological difficulties, then the model may be helpful in that respect. PNES patients have reported that they avoid engaging in meaningful activities for fear of having a seizure and fundamentally this drastically limits what they do and impacts negatively on how they feel. Furthermore, PNES patients that have engaged in exposure type techniques to help reduce anxiety demonstrated an increase in social and work related outcomes, as well as a reduction in fear of seizures and a reduction in frequency of seizures (Goldstein, LaFrance Jr., et al., 2010).

An ACT model for PNES may be helpful in aiding containment of fear and worry regarding seizures so that exposure to previously avoided stimuli can occur. Such preparation would include the practices of acceptance and mindfulness, whereas work on values may encourage clients to engage in previously feared situations in order to address some of difficulties they experience as a result of PNES phenomena.

1.5 The efficacy of Self-Help

The National Institute for Health and Care Excellence (NICE, 2004) define self-help as "a self-administered intervention designed to treat depression (sic), which makes use of a range of books or a self-help manual that is based on an evidence based intervention and is designed specifically for the purpose" (p. 358). The majority of published studies have focused on the efficacy of CBT based self-help interventions in reducing common mental health problems such as anxiety and depression (Bennett-Levy, Richards, & Ferrand, 2010) and there is some evidence to suggest that 'guided self-help' (with input from a therapist)

is more beneficial than ‘pure’ forms of self-help, that is, without any therapist input (Coull & Morris, 2011; Lewis, Pearce, & Bisson, 2012; Newman, Szkodny, Llera, & Przeworski, 2011; R. Richardson & Richards, 2010). Furthermore, a range of self-help approaches have been developed, including telephone support and internet based self-help approaches (Newman et al., 2011).

Benefits of guided self-help include wider access to psychological therapies which may otherwise be expensive and unavailable, reducing stigmas associated with mental health services, and extending psychological support to people that may not otherwise access it (Cavanagh, Strauss, Forder, & Jones, 2014; Cuijpers, Donker, van Straten, Li, & Andersson, 2010). The latter may be more pertinent to people who may not think psychological therapy would be helpful and are therefore more reluctant to seek psychological support, possibly due to having long-term physical health conditions or unexplained medical symptoms (M. Sharpe et al., 2011).

1.5.1 Self-help ACT

The documented success of self-help CBT approaches and the advent of third wave therapies has invited the investigation of ACT interventions delivered in a self-help format (Cavanagh et al., 2014). A recent meta-analysis and systematic review, conducted by Cavanagh and colleagues (2014), evaluated the effectiveness of acceptance and mindfulness based self-help interventions in fifteen studies in reducing health related symptoms and distress and anxiety and depression. Four of the studies used a self-help ACT based intervention for physical health conditions (pain and tinnitus); within these studies, significant increases in mindfulness and acceptance and reductions in symptoms and psychological distress were found following the intervention, suggesting that mindfulness and acceptance can be taught through self-help; furthermore, this supports the notion that increases in ‘psychological flexibility’ can be effective in reducing symptoms (Wicksell, Olsson, & Hayes, 2010).

In relation to self-help ACT interventions, Cavanagh et al.s (2014) review supported findings that guided self-help was more effective than ‘pure’ self-help interventions, given the larger treatment effect size for guided self-help.

However, the larger effect sizes observed in guided self-help interventions could be a result of a ‘higher dosage’ effect, or the notion that a therapeutic relationship appears to positively impact psychological treatment (Lambert & Barley, 2001; Reese et al., 2013).

Cavanagh et al.'s (2014) review highlighted two important points to take forward in relation to the current study; first, that high levels of engagement were associated with positive outcomes, and second, that further investigation of the mediating role of ACT processes is warranted. In relation to the first point, the current study ensured that engagement with the workbook was sustained via weekly telephone support; and in addressing the second point, the current study investigated possible mediating factors through repeated measurement of the ACT processes involved during the intervention (in addition to PNES phenomena).

1.5.2 Self-help PNES

A review of the extant literature suggests that there are no published studies investigating the efficacy of a self-help intervention for people with PNES. In a review of self-help interventions for medically unexplained symptoms (e.g. chronic pain, irritable bowel syndrome etc.), self-help interventions were found to have a medium effect size in reducing symptom severity and improving quality of life (van Gils et al., 2015). The majority of studies included in this review used a self-help intervention based on CBT, however, no significant differences were observed between interventions that included therapist contact and those that did not (van Gils et al., 2015). One study that investigated the efficacy of a guided self-help intervention (using a CBT model) for functional neurological symptoms found that guided self-help significantly improved subjective measurements of overall health after three months follow-up (M. Sharpe et al., 2011). These results were not sustained after the six month follow-up, which is consistent with findings that CBT approaches may not always be sufficient in managing symptoms in the longer term (Martlew, Pulman, & Marson, 2014).

Although no studies to date have investigated the efficacy of self-help intervention for a PNES population, evidence from a guided self-help study for functional neurology disorders (M. Sharpe et al., 2011) and chronic pain (M. Johnston, Foster, Shennan, Starkey, & Johnson, 2010) suggests that psychological interventions delivered in a self-help format may be beneficial for populations with these types of condition. Paired with the evidence that guided self-help and face-to-face therapies have comparable treatment effects (Cuijpers et al., 2009, 2010; Lewis et al., 2012), a guided self-help intervention for a group that finds face-to-face therapy difficult to engage in, may be clinically and practically relevant.

1.6 Clinical Relevance

PNES has a substantial impact on patients' lives and has been associated with reduced quality of life and functioning and high levels of psychosocial distress (Mercer et al., 2010). The current study determined whether ACT is a beneficial intervention for patients with PNES and whether broad psychological processes, such as psychological flexibility, impact PNES and psychosocial distress.

Presently, no 'gold standard' treatment for PNES has been suggested and although the research into CBT as a treatment option appears promising, further research is needed (Martlew et al., 2014). Furthermore, not only is more research needed in the area of psychological treatment for PNES, but the psychological nature of the condition often leaves patients confused or non-accepting of the diagnosis, therefore it is not surprising that engagement in psychological treatment for this population is poor (Baslet & Prensky, 2013). As such, any treatment approach will need to be acceptable to a PNES patient group if is to address these engagement issues.

Patients with PNES are often a marginalised group, who may be less willing or likely to seek psychological support and often make repeated unwarranted visits to physical health services (perhaps as a result of not fully understanding their

PNES diagnosis) and therefore driving up the costs of services (LaFrance Jr. & Benbadis, 2006). Although appropriate communication of the diagnosis is likely to aid understanding of PNES (Hall-Patch et al., 2010; Tammaa et al., 2011), appropriate treatment may not be readily available, which may lead to the condition becoming more chronic if not treated swiftly (Bodde et al., 2009). Psychological treatment for PNES therefore needs further investigation, and importantly, key mechanisms for change in psychological interventions should be identified in order assess the validity of such treatments.

The current study used a single-case experimental design to assess which ACT processes mediated change in PNES phenomenon, which validates the use of specific processes within psychological treatment for PNES. In addition, self-help interventions have been evidenced as being just as effective as formal face-to-face therapy (Cuijpers et al., 2010) and are more cost-effective (Lewis et al., 2012), therefore the current study employed a guided self-help format to widen access to psychological support for a PNES population which would be a cost effective way to help patients on a larger scale.

2 Extended Method

2.1 Inclusion Criteria

- Seizure frequency:

It was assumed that participants may not have been able to accurately recall the exact number of seizures they had had in the past month, therefore, 'three seizures or more' was used as the cut -off point for inclusion in the current study (based on inclusion criteria from previous PNES/epilepsy treatment studies (Goldstein, Chalder, et al., 2010; Lundgren et al., 2006)). However, accurate recordings of seizure frequency were collected daily during the baseline phase, which was used to compare against seizure frequencies at post-treatment and follow-up.

- Cut off scores on quality of life and psychological distress measures:

PNES is associated with reduced quality of life and high levels of psychological distress (Szaflarski, Szaflarski, et al., 2003; Szaflarski & Szaflarski, 2004), however, Binzer, Stone and Sharpe (2004) and Stone et al. (2015) found that patients with PNES were likely to underreport emotional/psychiatric symptoms. Therefore, the use of cut off scores on measures of quality of life and psychological distress may have inadvertently excluded participants with higher quality of life/lower distress scores who were seeking support for managing their seizures, thus, cut-off scores were not used in the current study.

- Diagnosis:

Confirmed diagnosis via VEEG monitoring, neurologist or PNES specialist was required for inclusion in the study; this was to ensure that participants who were taking part had confirmed and not suspected PNES. Participants were not excluded on the basis of having a comorbid diagnosis of epilepsy, however, only participants that were able to reliably distinguish between them were included. This was to ensure that the seizures reported were PNES and to reliably assess any changes in non-epileptic seizures as a result of the intervention.

- Age:

The study's aim was to investigate the effects of an ACT intervention for adults with PNES, therefore, individuals under the age of 18 were excluded from the study. This was included as advertisements were placed on social media groups which may be accessible to people under 18 years old.

- Current psychological therapy:

The current study investigated the effects of an ACT intervention for PNES, therefore individuals in current receipt of psychological interventions targeted at helping them manage their seizures were excluded. This was to ensure that any changes observed during the study period were due to the ACT intervention and not the result of any other psychological treatment.

- Comprehension:

The ACT workbook was written in English and participants would be contacted and have weekly telephone support with an English-speaking researcher, therefore, only participants' whom had a good understanding and comprehension of the English language were included; this was also assessed during the initial telephone contact with the researcher.

2.2 Epistemology and Single-case Experimental Designs

2.2.1 Functional Contextualism

The philosophical framework of ACT is based on functional contextualism. Functional contextualism (FC) is a pragmatic, post-positivist position which posits that all behaviour has a function within the context it occurs. The aim of the applied practitioner is to predict and influence behaviour through targeting and manipulating change variables (Biglan & Hayes, 1997). Thoughts, beliefs, emotions and overt behaviours are viewed as 'dependent variables' and within FC only contextual events are considered able to directly predict and influence consequences, rather than the direct manipulation of dependent variables themselves (Hayes, 1995). For example, if the thought "if I have a seizure I'll I ruin everything" occurs within a context where thoughts are experienced as

rules that govern behaviour, then this thought may be linked with avoidant behaviours (e.g. avoiding social events). However, if the same thought occurred in a context where thoughts were experienced as habits, sounds or verbal relations, rather than rules for behaviour, then the thought may not be connected with avoidant behaviour (Hayes et al., 1999).

From a FC perspective, thoughts are not considered to result in emotional responses; they are not considered to be rational or irrational, nor are the content of thoughts or evidence for thoughts important. Of importance is the function of the thought within the particular context in which it occurs (Ciarrochi, Robb, & Godsell, 2005). The fundamental concern of FC is the functional relationship between psychological events (such as thoughts, beliefs, emotions etc.) and the current context ('manipulable' events in the environment). In order to evaluate current and historical contexts that predict and influence behaviour with precision, scope and depth, it is necessary to systematically manipulate variables within the person's environment and measure the impact of this on the psychological event of interest (Biglan, 1995). Methodologies that are able to isolate which contextual factors instigate change are therefore necessary for FC research; group comparison and single-case experimental designs are useful in this regard as they are able to suggest which contextual (independent) variable influences events (J. D. Smith, 2012). Furthermore, single-case experimental designs are considered the most effective methodology in investigating contextual behaviour change (J. D. Smith, 2012).

2.2.2 Single-case Experimental Designs

Single-case experimental designs (SCEDs) are often used in behavioural research to investigate psychological processes and behavioural outcomes resulting from manipulations in the SCED (Borckardt et al., 2008; J. D. Smith, 2012). An advantage of using a SCED is that any observed changes can be attributed to the efficacy of the treatment, rather than as a result of chance or other confounding variables (Rassafiani & Sahaf, 2010). Furthermore, SCEDs have the capacity to measure changes in individual differences through the collection of detailed time-series data; a methodology that gives scope to understanding populations in which high levels of heterogeneity are often

observed (Barlow, Nock, & Hersen, 2009). Therefore, a methodology such as the SCED lends itself well to addressing the aims of the current study.

SCED research often requires a smaller sample size than that of group or comparison designs, this is due to the focus on individual difference, rather than group differences. Although SCEDs are similar to case study research designs in terms of sample size and focus on individual differences, they differ as SCEDs are used to generate and test hypotheses and establish cause and effect relationships using multiple participants (Rassafiani & Sahaf, 2010).

Traditionally, SCEDs take the form of a 'withdrawal' or ABA design. ABA designs typically consist of a time period of no treatment (A), followed by a period of treatment (B), ending with the treatment being withdrawn and another period of no treatment (A). The aim of the ABA design is to make causal relationships between the effectiveness of a treatment (independent variable) and the outcome of interest (dependent variable) within the subject. However, there are limitations with using such a design; firstly, there are practical limitations of testing the efficacy of treatments that cannot be unlearnt, such as psychotherapy, and secondly, the ethical implications of withdrawing potentially ameliorative treatment (Rassafiani & Sahaf, 2010). Given the limitations of an ABA design, it was not deemed appropriate for use in the current study.

A SCED methodology that addresses some of the limitations of the ABA approach is the AB design; this allows for a causal relationship to be established without the need to withdraw treatment. The AB design is similar to the ABA design inasmuch as there is an initial no treatment/baseline period (A) followed by a period of treatment (B). In a multiple-baseline (MB) design across participants (rather than across behaviours or settings), each participant begins the baseline phase at different times. Within this design, repeated measurements of the target behaviours (dependent variables) are collected during the baseline phase and during the treatment phase. The baseline phase acts as the participant's control, meaning that any changes observed during the treatment phase (accounting for variations observed during baseline) can be attributed to the intervention (J. D. Smith, 2012). If the same changes are

repeatedly observed across multiple participants, then this provides further support for the effectiveness of the intervention.

MB designs can be concurrent or non-concurrent. In a concurrent MB design, at least two participant's baselines require evaluation within the same time period; the intervention is then applied to the participant with the most stable baseline and only after an intervention effect is demonstrated is the intervention applied to the next participant (J. M. Johnston, Pennypacker, & Green, 2008). Concurrent MB designs are the most common MB designs and control for threats to internal validity, including historical events that may concurrently effect multiple participants and maturation/exposure to clinical/experimental context (Barlow et al., 2009). However, it may not always be practical or possible for participants to begin the baseline phase concurrently, therefore, the use of non-concurrent MB designs can be implemented. Non-concurrent MB designs are more flexible than concurrent designs and allow for participants to be evaluated (non-concurrently) at different time points (Watson & Workman, 1981). Non-concurrent MB designs control for threats to maturation/exposure, however, they are limited in their ability to control for historical threats to internal validity (Carr, 2005). Nonetheless, non-concurrent MB designs are able to demonstrate prediction and replication, and are often a sufficient means of evaluation when historical effects are unlikely to affect all participants (Carr, 2005).

The current study employed the use of a non-concurrent multiple base-line design because: (i) participants came forward to take part at different time points, (ii) treatment could not be withdrawn, and (iii) the primary aim of the study was to investigate the effects of a staggered ACT intervention on various measures. The intervention phase of the study contained the six core ACT processes, therefore, the intervention phase was split into six phases, allowing the introduction a different ACT process each week (see Journal Paper Figure 2 and Table 2). The design also allowed inferences to be made about specific ACT processes in reducing PNES phenomena (if observed across multiple participants).

2.3 Psychometrics

2.3.1 Selection of measures

A review of the extant literature was carried out to assess the different measures used for measuring quality of life and psychological distress in PNES. Furthermore, as participants were to complete measures daily and weekly over at least seven weeks a key consideration when selecting measures was to ensure that the repetitive nature of completing measures would not become over-burdensome for participants; for this reason, short form measures were selected where possible. Four measures were used in the weekly battery of questionnaires which are described below. (See Journal paper 2.3.2 for information on selection of the daily measures).

2.3.2 The Quality of Life in Epilepsy Inventory

Physical illnesses often correlate poorly with a person's functioning capacity and psychological wellbeing, therefore, it was important to measure health related quality of life (HRQoL) and the impact chronic illness has on quality of life (Mercer et al., 2010). Domains of HRQoL include: physical functioning (self-care/mobility), emotional functioning (anxiety/depression or wellbeing) and social functioning (relationships with others/relationships within a wider societal or cultural context) (Romney & Evans, 1996). Disease-specific instruments have an advantage over generic HRQoL measures in that they have the potential to increase responsiveness by including only aspects of HRQoL that are relevant to the patient group of interest.

The most commonly used HRQoL measures within a PNES population include generic HRQoL measures, such as the Short Form-39 (SF-39), and disease specific instruments, such as the Quality of Life Inventory-89 (QOLIE-89) and its respective short form versions (e.g. QOLIE-31 and QOLIE-10). The QOLIE inventories have been validated in epileptic populations but are commonly used with PNES patient groups; they contain generic quality of life items (incorporated from the SF-36) with additional items relating to seizure worry/fear and medication effects (Leone, Beghi, Righini, Apolone, & Mosconi, 2005).

As reduced quality of life is often reported by people with PNES in comparison with epileptic and normal populations (Quigg, Armstrong, Farace, & Fountain, 2002; Szaflarski, Hughes, et al., 2003; Testa et al., 2007) it was important that the current study examined how the intervention impacted on quality of life. Furthermore, based on ACT theory that experiential avoidance and cognitive fusion underlie PNES phenomena and the time-consuming nature of taking part in the study, it was important to utilise a quality of life measure that included items describing fear or worry about seizures and that was also the least burdensome; therefore, the QOLIE-10 was selected.

The QOLIE-10 (Cramer, Perrine, Devinsky, & Meador, 1996) correlates adequately with the QOLIE-31 subscales ranging from r=.54 (social functioning) to r=.73 (mental effects). However, full scale internal consistency of the QOLIE-10 was not reported and the reliability of each subscale (epilepsy effects, mental health and role functioning) failed to reach the required standard of ≥ 0.8 (Cramer et al., 1996; Nixon, Kerr, Breheny, & Wild, 2013). Further searches of the extant literature revealed that translated versions of the scale meet the required standard for internal consistency when the item regarding 'trouble with driving' is removed or changed to 'trouble with transportation'; reflecting that many people with PNES are unable to drive. Therefore, the item regarding driving was changed and the normative (comparative) data from the Chinese translated version of the scale was used to calculate reliable and clinically significant change (Gao, Xia, Pan, Xiong, & Li, 2014). The mean of the Chinese epilepsy group did not differ significantly from the mean of other epilepsy groups on the QOLIE-10, which were 23.41 (SD=7) and between 22.1 (SD=8.95) and 28.1 (SD=8.7), respectively (Bautista & Tannahill Glen, 2009; Jehi, Tesar, Obuchowski, Novak, & Najm, 2011). Therefore, the normative data derived from the Chinese QOLIE-10 was used as the comparison group when calculating reliable and clinically significant change, given that this version offered reliability that meets the required standards.

2.3.3 Depression Anxiety and Stress Scales 21

Although individuals with PNES report reduced quality of life, the impact of seizures themselves may not be directly linked with quality of life overall

(Mercer et al., 2010). Instead, some researchers argue that underlying psychopathology is closely linked to PNES and may be a larger contributing factor in quality of life (Lawton, Mayor, Howlett, & Reuber, 2009; Szaflarski & Szaflarski, 2004; Testa et al., 2007).

There is an abundance of anxiety and depression scales available; however, the utility of the Depression Anxiety and Stress Scales 21 (DASS-21; (S. H. Lovibond & Lovibond, 1995) to assess three constructs concisely was advantageous within this study. The DASS 21 is a short form measure of the 48-item DASS measure. Studies have shown that the DASS 21 has a similar factor structure and gives the same results as the full DASS scale and has good convergence with other depression and anxiety measures (Antony, Bieling, Cox, Enns, & Swinson, 1998; P. F. Lovibond & Lovibond, 1995). Furthermore, the DASS 21 has been widely used in clinical and non-clinical samples and within the field of physical health (including PNES), hence, results are comparable with other PNES research (Baslet, Dworetzky, Perez, & Oser, 2014; Baslet, Roiko, & Prensky, 2010; Ng et al., 2007).

2.3.4 The Comprehensive Assessment of Acceptance and Commitment Therapy processes

Previous ACT measures have focused on theoretical sub-processes of ACT, including acceptance/experiential avoidance (Gámez et al., 2014), cognitive defusion/fusion (Gillanders et al., 2014), present moment awareness (Brown & Ryan, 2003) and values (Wilson, Sandoz, Kitchens, & Roberts, 2011). Although these sub-process measures may be helpful in determining the impact of a single process on behaviour, they do not capture the broader ACT process of overall psychological flexibility. Single measures could be combined; however, this would result in undue response burden and difficulties in interpreting data may arise as a consequence of combining different analytic models. To address these issues, Francis, Dawson, & Golijani-Moghaddam (2016) developed the Comprehensive Assessment of Acceptance and Commitment Therapy processes measure (CompACT).

The CompACT has not been used extensively due to its recent development, however, it was shown to have good convergent validity with another ACT process measure (the Acceptance and Action Questionnaire; AAQ II) (r=0.79) and good concurrent validity with all three subscales on the DASS-21 (0.57-0.65). Furthermore, the CompACT was shown to have good internal consistency for the full scale (α=0.91) and in all three subscales (α=0.87-0.90). The utility of the CompACT to measure overall psychological flexibility and sub-processes reliably was advantageous in the present study for both reducing participant response burden and addressing one of the main aims of the study.

2.3.5 The Acceptance and Action Questionnaire II

Although the CompACT was used as the main measure of ACT processes within the current study, it is a recently developed instrument with limited evidence base for its use within clinical samples. As such, it was prudent to include another measure of psychological flexibility often used within ACT research.

The AAQ II (Bond et al., 2011) was developed to assess the effectiveness of ACT interventions and measures acceptance and experiential avoidance; however, it is the most widely used instrument for measuring psychological flexibility in ACT research (Ruiz, Langer Herrera, Luciano, Cangas, & Beltrán, 2013). Although the AAQ II has shown good test-retest reliability at 3 months (0.81) and 12 months (0.79) and has good internal consistency (α=0.84) (Bond et al., 2011), it has been criticised for conflating ACT processes with outcome variables of distress (Wolgast, 2014). Nonetheless, the AAQ II has empirical support from a number of studies (Ruiz, 2010) and is the current 'gold standard' for measuring psychological flexibility (Schmalz & Murrell, 2010). However, the implementation of another measure that has the ability to explicitly examine other important ACT processes, such as committed action, was also important. As such, the inclusion of the CompACT in the current study was necessary.

2.4 Procedure

2.4.1 Initial stage

Participants that had come forward after seeing the advertisement were sent the participant information sheet (see Appendix A) and invited to discuss the study in more detail with the researcher, which included a discussion of the different phases of the study and how the online daily and weekly measures would be accessed and completed. This also gave participants the opportunity to ask any questions about the study.

After participants had read the participant information sheet and had discussed the study with the researcher, they were emailed a link to the online informed consent form (see Appendix B) if they agreed to take part in the study. Once informed consent was received, participants were then asked to complete the online screening questionnaire to ensure that participants satisfied the inclusion criteria for the study. If participants met the inclusion criteria, they were then asked to complete the battery of weekly questionnaires. Participants received introductory chapters of the book '*Get out of your mind and into your life'* (Hayes & Smith, 2005) to help socialise them to the ACT model prior to beginning the study.

2.4.2 Baseline phase

Participants were then asked to complete the daily measures for at least a week. Participants received either an email or a text message containing the website link to complete the daily questionnaire, depending on their preferences stated in the initial discussion with the researcher. All online questionnaires were created using the website: www.qualtrics.co.uk.

After a week, the daily measures were plotted to allow visual inspection of the baseline data. Participants began the intervention phase of the study if no improvement or a deteriorating baseline trend was demonstrated for a minimum of three consecutive days. If the visual inspection revealed an improvement on the daily measures, then participants were required to continue completing their

daily measures for a further seven days or until a stable baseline was established.

Following successful completion of the baseline phase, participants were asked to complete the battery of weekly measures again (via the online website) prior to commencing the intervention phase.

2.4.3 Intervention phase

Once a stable baseline had been achieved, participants were sent corresponding ACT process chapters from the workbook, '*Get out of your mind and into your life'* (Hayes & Smith, 2005). Participants were sent the (i) *acceptance* chapters on commencement of the intervention phase and were required to read the chapters over the next week. A suitable time was arranged with each participant on when they would be contacted by the researcher to support them with the self-help material, assess their engagement with the workbook, answer any queries relating to the relevant chapter and to assess any external events that may have impacted on their completion of the chapter that week. Following the researcher contact/support, participants received an email/text with the website link to access the battery of weekly measures and were asked to complete them. Participants then received the next ACT process chapter(s): (ii) *cognitive defusion* to read over the next week. The same process was followed each week for subsequent ACT process chapter(s); (iii) *self as context,* (iv) *present moment awareness,* (v) *values,* and (vi) *committed action*.

The chapters were distributed in this systematic fashion to (i) prevent participants reading ahead and (ii) so that any observed changes could be attributed to the specific ACT process being measured. Furthermore, as participants came forward to participate in the study at different times, stronger inferences could be made regarding the impact of the self-help material and possible mechanisms of change; as no participants completed the same ACT process chapters at the same time it could be inferred that any observed changes (e.g. distress related to seizures) were likely due to that ACT process (e.g. present moment awareness), rather than any other external factors.

2.4.4 Follow-up and change interview

Participants were asked to complete the online daily and weekly measures at one week following the intervention and again one month following the end of the intervention. At the one-month follow-up period, participants were also asked to engage in a change interview (Elliott, Slatick, & Urman, 2001) with an independent researcher (a trainee clinical psychologist) who was blind to all participants' results on all measures. The change interview used the same framework set out by Elliott et al.'s (2001) change interview protocol however some questions were adapted for use in the current study (see Appendix F for change interview questions). Principally, the change interview allowed individuals to comment on their experience of psychotherapy in regards to what they found helpful and important during the intervention, whether any changes resulted from the psychotherapy and any other elements responsible for perceived change (Elliott, 2010). The change interview was used in the present study to support or contest findings from the quantitative analysis. Following the change interview, participants were thanked for their time and received payment for participating in the study (a total of £40).

2.5 Ethical Considerations

The current study was carried out in accordance with the British Psychological Society's code of human research ethics (BPS, 2010). Ethical approval of the current study was granted by The University of Nottingham School of Medicine Research Ethics Committee (see Appendix D for confirmation of ethical approval).

Potential participants that responded to the advertisements were given information regarding the nature of the study and were emailed a copy of the participant information sheet (see Appendix A). If potential participants still wanted to take part in the study after reading the participant information sheet, they were invited to discuss the study in more detail with the researcher and ask any questions via telephone. Participants were informed of the experimental

nature of the study; hence, the ACT intervention may not achieve the result they, or they researcher, hoped for.

Once participants understood the nature of the study and the level of commitment required, they received a website link via email where they gave their informed consent (www.qualtrics.co.uk) (see Appendix B). Informed consent was obtained prior to participants completing any questionnaires or beginning the baseline phase. Consent forms were stored on the website's secure database which were printed and stored in a locked cabinet in the University of Nottingham when the study finished.

To ensure participant confidentiality, participants were allocated a unique identifier which was made up of the first three letters of their mother's maiden name and their date of birth (e.g. NOR21). The identifier, and the participant information it was connected to, was stored on a password-protected memory drive that was only accessible to the researchers. Participant identifiers were used to identify participants throughout the data collection and analysis phases of the study. Participants were informed that their anonymity would be protected throughout the study and in any dissemination of the research.

When participants completed the daily and weekly online measures, they were provided with a unique hyperlink to the website hosting the measures (www.qualtrics.co.uk). The results of these measures were accessible only to the researchers through the password-protected website.

Participants were made aware that participation in the study was entirely voluntary and that they could withdraw from the study at any time without giving any reason and that any data collected may still be used in the analysis of the study. Participants received monetary compensation for taking part in the study due to the intense involvement during the study period, based on the length of participation. A value of £5 for each intervention phase of the study completed and £10 after the one-month follow-up change interview (£40 total) was deemed a fair reimbursement for participants' time. On completion of the study, participants were asked if they would like to receive a summary of results after

data analysis. Results summaries were emailed to participants at their request, following data analysis.

2.6 Reliable Change Index and Clinically Significant Change Methods

If an individual makes Reliable Change (RC) and Clinically Significant Change (CSC) following a psychotherapeutic intervention, then changes are deemed to be meaningful. Jacobson and Truax (1991) suggested two ways in which RC and CSC could be calculated.

2.6.1 Reliable Change (RC)/Reliable Change Index (RCI)

The Reliable Change Index (RCI) is a statistic used to detect whether a change in an individual's post-treatment score is statistically significant to their pre-treatment score (measurement variability). Essentially, Reliable Change (RC) is demonstrated if the change falls beyond the range of the variance of the measure. RCI is calculated by taking the change in the individuals score and dividing it by the 'standard error' (SE) of the difference of the measure used. The RCI value indicates by how much an individual's score must change (either increase or decrease) in order for change to be deemed reliable and not a result of chance (at 95% confidence) (Jacobson & Truax, 1991).

RCI is the individual's pre-treatment score (X^1), taken from their post-treatment score (X^2), divided by the standard error of difference (S_{diff}) of the test (calculated using standard deviation and internal consistency of the test) (see Figure 22).

$$RCI = \frac{X^2 - X^1}{S_{diff}}$$

Figure 22. Formula for calculating RCI (Jacobson & Truax, 1991)

In order for the standard error of difference (S_{diff}) to be calculated, the standard error of measurement (*SEM*) must first be calculated. The *SEM* is the standard

deviation of test takers scores (*SD*) multiplied by the square root of one minus the tests reliability coefficient (r) (see Figure 23). Once the *SEM* has been calculated, the S_{diff} can then be calculated (see Figure 24).

$$SEM = SD\sqrt{1-(r)}$$

Figure 23. Formula for calculating the standard error of measurement

$$S_{diff} = SD\sqrt{2\,(SEM)^2}$$

Figure 24. Formula for calculating the standard error of difference

For example, if the difference between the individual's pre-treatment score (e.g. 42) and post-treatment score (e.g. 60) is greater than the RCI value (e.g. 8.34), then the individual is deemed to have made a reliable change at 95% confidence, however, if the difference in scores is not greater than the RCI value, then any changes observed cannot be deemed as reliable (Jacobson & Truax, 1991).

2.6.2 Clinically Significant Change (CSC)

If an individual has made a reliable change, then their post-treatment score can be examined in more depth to determine whether this change is clinically meaningful; that is, how the post-treatment score compares with the scores of others in socially and clinically relevant comparison groups (Evans, Margison, & Barkham, 1998).

Jacobson and Truax (1991) described how CSC could be calculated using one of three criteria for determining CSC cut-off points:

- Criterion a: the individual's post-treatment score is two standard deviations *away* from the mean of **clinical** group.

- Criterion b: the individual's post-treatment score is two standard deviations *within* the mean of a **non-clinical** group.
- Criterion c*:* the individual's post-treatment score is *closer* to the mean of the **non-clinical** group than the mean of the clinical group.

Figure 25 displays Jacobson and Truax's (1991) CSC cut-offs determined by each of the three criterion using a graphed visual display.

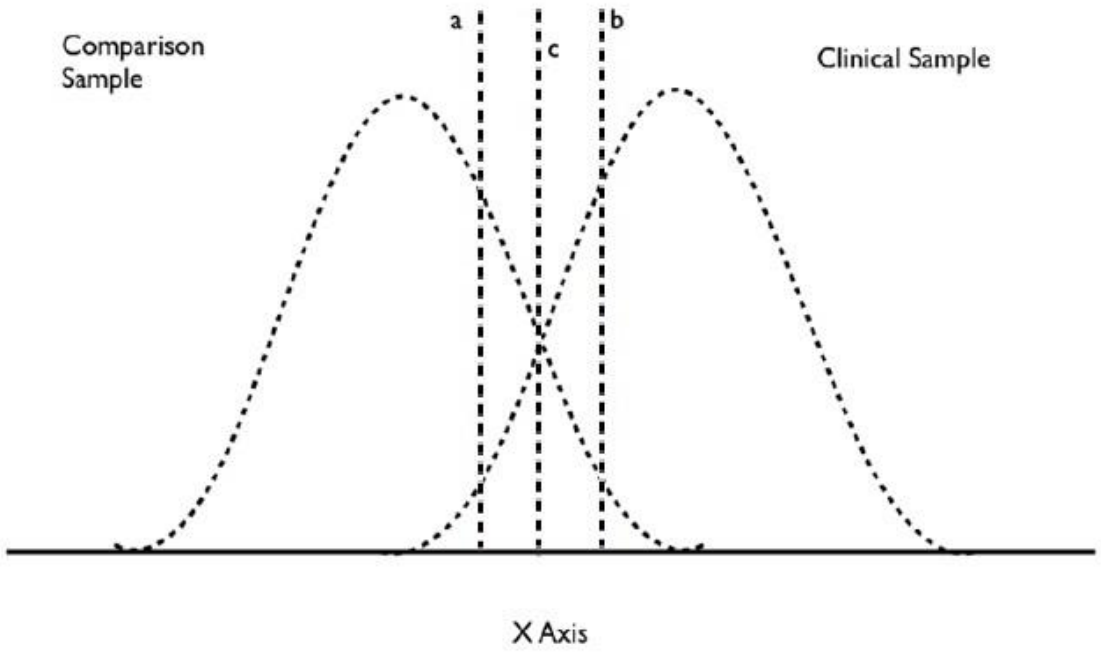


Figure 25. Graphed representation of Jacobson and Truax's (1991) three statistical criteria for defining CSC

2.6.3 RCI and CSC Critique

RCI and CSC methods have utility in determining change as an effect of a psychotherapeutic intervention at an individual level, rather than by comparing the means of group pre-and-post data (Wise, 2004). However, these methods are not without their limitations: Kazdin (1999) suggested that symptom reduction was not the 'gold standard' for determining clinically significant change and that although treatment effectiveness could be based on symptom reduction, this neglected a host of other viable factors for clinically meaningful change, such as quality of life and functionality. Furthermore, Kazdin (2001)

argued that using symptom reduction as a primary criterion for assessing significant change demonstrated no evidence that this would effectively convey the individual from one 'dysfunctional' threshold to a 'functional' threshold regarding their daily functioning, nor that no change necessarily meant treatment was unsuccessful. Kazdin (2001) argued that significant change outcomes should be aligned with the clinical goals and lives of the individual in order to detect clinically meaningful change.

Another criticism of using reliable and clinically significant cut-offs is that small changes which do not meet the cut-off criteria are regarded as errors in measurement, whereas in some cases, a small change may represent a meaningful shift for the individual (Hageman & Arrindell, 1993). Furthermore, as individuals are more likely to come into contact with services, or seek help when they are 'in crisis' or form part of a 'dysfunctional' group, there is a greater likelihood of regression towards the mean and thus influencing RCI (Martinovich, Saunders, & Howard, 1996). Nonetheless, RCI and CSC methods have withstood scientific debate and allow the investigation of individual treatment effectiveness; a shift from the general comparison of group means (Wise, 2004). It is important, given these criticisms, that relevant contextual measures for assessing functionality and symptom reduction are used when examining the effectiveness of psychological treatment (Wise, 2004).

The present study examined both the effects of functional ability and symptom reduction as a result of the guided self-help ACT intervention. This was achieved by measuring distress symptoms, aspects related to quality of life, psychological flexibility and seizure frequency, although the latter was not subject to RCI and CSC methodology. In addition, participants were asked about perceived changes as a result of the intervention in the final change interview. The importance of including a range of both functional and symptom related measures was imperative to the current study, as within an ACT framework, symptom reduction is not the primary goal of ACT, rather, increasing psychological flexibility is (Hayes, Luoma, Bond, Masuda, & Lillis, 2006).

2.6.4 The use of RCI and CSC methodology in the present study

In order to calculate RCI and CSC, the most accurate results are obtained by using the standard deviations of the test-takers scores and the reliability of the measure used (Jacobson & Truax, 1991). However, this presents a problem when using small samples, as in SCED research. To overcome this, it is then advisable to calculate RCI and CSC using data derived from large samples (means and standard deviations) of the measure of interest, along with the reliability of the measure, preferably using a sample that is closest to the sample in question (Jacobson & Truax, 1991). Therefore, where possible in the current study, clinical data from published studies utilising the measures subject to RCI and CSC methods in the current study, applied to a PNES population, were used to calculate RCI and CSC. Some of the measures subject to RCI and CSC in the present study could not be found from a suitable PNES or epileptic sample; in those cases, the data from the study's sample were used to tentatively assess RCI and CSC.

Table 8 displays the information on the studies used to calculate RCI and CSC cut-offs, along with the clinical sample used, for the current study.

Table 8. Studies, measures and clinical samples used to calculate RCI and CSC in the present study

Measure (construct)	Study	Clinical sample
DASS 21 (psychological distress)	Baslet et al. (2010)[3]	PNES (split the sample into 3 groups: psychological burden; physical burden; no burden)
QOLIE-10 (quality of life)	Quigg et al. (2002)	PNES
AAQ II (acceptance/experiential avoidance)	Current study	PNES
	(Panayiotou et al., 2015)*	Alexithymia*
CompACT (psychological flexibility)	Current study	PNES

*Notes: DASS 21- depression, anxiety and stress scale; QOLIE-10- quality of life in epilepsy inventory; AAQ II- Acceptance and action questionnaire; CompACT- Comprehensive assessment of acceptance and commitment therapy processes; PNES- psychogenic non-epileptic seizures; * for illustrative purposes*

[3] Baslet et al. (2010) divided their PNES sample into three groups based on: prevalence of neurological symptoms, such as epilepsy or stoke etc ('neurological burden); psychological symptoms, including psychiatric diagnoses and symptoms of anxiety/depression etc. ('psychological burden'); or those that did not appear to have neurological or psychological symptoms ('no burden').

The clinical sample types used for calculating RCI and CSC for the present study all used a PNES sample, albeit, for the CompACT and AAQ II, the current study's data was used. With reference to the DASS 21 and QOLIE-10, although a PNES sample type was used for the clinical data, it would be prudent to assess the homogeneity of the clinical samples used with the current study's sample, given the reported heterogeneity among people with PNES. Given this heterogeneity, Baslet et al. (2010) separated their sample into three groups, therefore it is also important to assess whether each group mean is homogenous with the current studies sample, if separated into the same groups.

Even though the clinical reference sample type is the same as in the present study (for the QOLIE-10 and DASS 21), if RCI and CSC cut-off scores are much higher or lower than they would have been using the current study's sample data, then the cut-offs used may not be appropriate for the calculating meaningful change for participants in the present study.

To examine the homogeneity between the clinical reference samples used to calculate RCI and CSC cut-off scores and the current study's sample, the pre-treatment score means for both samples were compared. Although the current study utilised data from the current sample for the AAQ II, a clinical reference sample is also supplied for illustrative purposes. Table 9 provides information regarding both the clinical reference and current study samples.

Table 9. Current study sample means and clinical reference sample means used to calculate RCI and CSC

Measure	Current sample mean (SD) pre-treatment score	Clinical reference sample mean (SD) pre-treatment score
DASS 21	11 (1.41) NB 59 (18.94) PB	31.14 (19.67) NB 37.82 (19.13) PB
QOLIE-10	28.5 (8.83)	25.2 (1.40)
AAQ II	24.17 (8.07)	22.85 (8.39)*
CompACT	68.5 (32.11)	-

The information displayed in Table 9 indicates some degree of homogeneity between the current sample means and clinical reference sample means for the DASS 21 psychological burden and no burden groups, as the current sample means are within two standard deviations of the clinical reference sample. There appears to be less homogeneity between the two samples for the QOLIE-10 measure, as the current sample mean is two and a half standard deviations away from the clinical reference sample mean. As such, care should be taken when interpreting meaningful change for this measure. In relation to the DASS 21, it appears that in the current sample, the 'no burden' (NB) group is less distressed than the NB group in the clinical reference sample, however, the 'psychological burden' (PB) group appears more distressed in the current sample than in the clinical reference sample. However, the current study sample appear to have more difficulties in relation to aspects of quality of life than the clinical reference group. Taken as a whole, the current study sample appeared to be slightly worse off than the clinical reference group.

The AAQ II and CompACT current study sample data were used to calculate RCI and CSC cut-off scores as no appropriate clinical reference groups were found. The CompACT is a recently developed measure and has not been widely used; the only current data available to date is comparative normative data (i.e. no clinical data is yet available) (Francis et al., 2016). The AAQ II has been used with various clinical populations, however, a search of the extant literature revealed that the AAQ has not been utilised with a PNES population. Furthermore, when a search was conducted for the use of the AAQ II within an epilepsy population (a group commonly compared with PNES) only an adapted version of the AAQ for epilepsy was available (Lundgren, Dahl, & Hayes, 2008); comparisons between epilepsy and PNES groups are questionable given the reported involvement of other psychological factors for PNES and the reportedly distinct profiles between the two conditions (Mercer et al., 2010; Szaflarski & Szaflarski, 2004; Testa et al., 2007). A clinical reference sample for the AAQ II utilising a Greek population with Alexithymia was evaluated and homogeneity was found between the two samples; however, as the clinical reference sample population was not a PNES sample and the scores between the two samples were highly homogenous, it was decided that the current study sample would

be more appropriate for use in the current study. Therefore, due to the lack of appropriate clinical reference samples available using the AAQ II and CompACT, it was deemed appropriate to use the current sample data for calculating RCI and CSC cut-off scores, as recommended by Jacobson and Truax (1991).

The QOLIE-10 showed the least homogeneity between the current study sample and the clinical reference sample, however, the CSC cut-off score would not have differed significantly if either sample was used (current study CSC cut-off=25.66; clinical reference sample CSC cut-off=24.90), whereas the RCI differs on the sample used (current study sample RCI value=9.38 vs. clinical reference study sample RCI value=1.49). Indeed, participants were required to change ≥ 1.49 on the QOLIE-10 in order for change to be deemed reliable, which may be considered too small an amount. However, if the current sample data were used, it may mean that participants would have to demonstrate a much larger change (≥ 9.38) on the measure when this is based on a relatively small sample size.

Wise (2004) recommended that other factors should be considered when examining the effectiveness of a psychotherapeutic intervention, given the criticisms of using RCI and CSC methods and the differences highlighted between the current study sample data and clinical reference sample data. As such, the current study also evaluated changes in personal seizure frequency reports (which could be compared with any change data) and the final change interview when making inferences about the effectiveness of the guided self-help ACT intervention.

2.7 Statistical methods for time-series analysis

Visual inspection and statistical analysis of time-series data are usually used to evaluate whether the independent variable had any significant impact on behaviour. Visual inspection is usually necessary in single-case data analysis as no other method can adequately convey the variance of outcome data over

time, however, visual inspection is open to researcher interpretation which may lead to increased Type I errors (Barlow et al., 2009). The use of statistical analysis alongside visual inspection of time-series data can enhance the evaluation of the data; clinically reliable and clinically significant change analysis are statistical methods that can be applied to SCED research (Kazdin, 1999), which were implemented in the current study (see previous section). However, another statistical method that could be applied to SCED research is the t-test.

Traditional t-tests compare differences between two (t-test) or more (ANOVA) groups. In single case designs, comparing between 'groups' in traditional t-test analysis becomes comparing between 'phases' and within group variance becomes within phase variance. T-tests for SCED analysis is calculated by dividing the differences between phases with the collective within-phase variance. In the current study, a t-test could be used to assess whether the difference between the mean-level of the baseline phase (A) is significantly different to the intervention phase as a whole (B), or an ANOVA could be used to evaluate the statistical difference between the baseline and each of the six intervention phases. However, using t-tests with single case data can be problematic as the main assumptions for t-tests may be violated in single case designs (Barlow et al., 2009; Crosbie, 1993). For example, data collected in single case research often violates the assumption of normality, especially when the observation of outcomes occurs episodically throughout the study, in this case, the frequency of seizures. Secondly, in time-series single case designs, statistical dependencies of the data often occur, which is that observations collected adjacent or near each other are more similar to each other than they are to the mean, thus violating the t-test assumption that data in each phase are independent (Barlow et al., 2009), therefore, t-tests and ANOVAs are not ideal to use in single case research. In the current study, visual inspection, CSC and RCI methods were appropriate for evaluating differences between phases and assessing clinically significant and reliable change for participants; for further discussion of RCI and CSC methods and their limitations see the previous section.

3 Extended Results

3.1 Analysis of weekly full-scale outcome measures

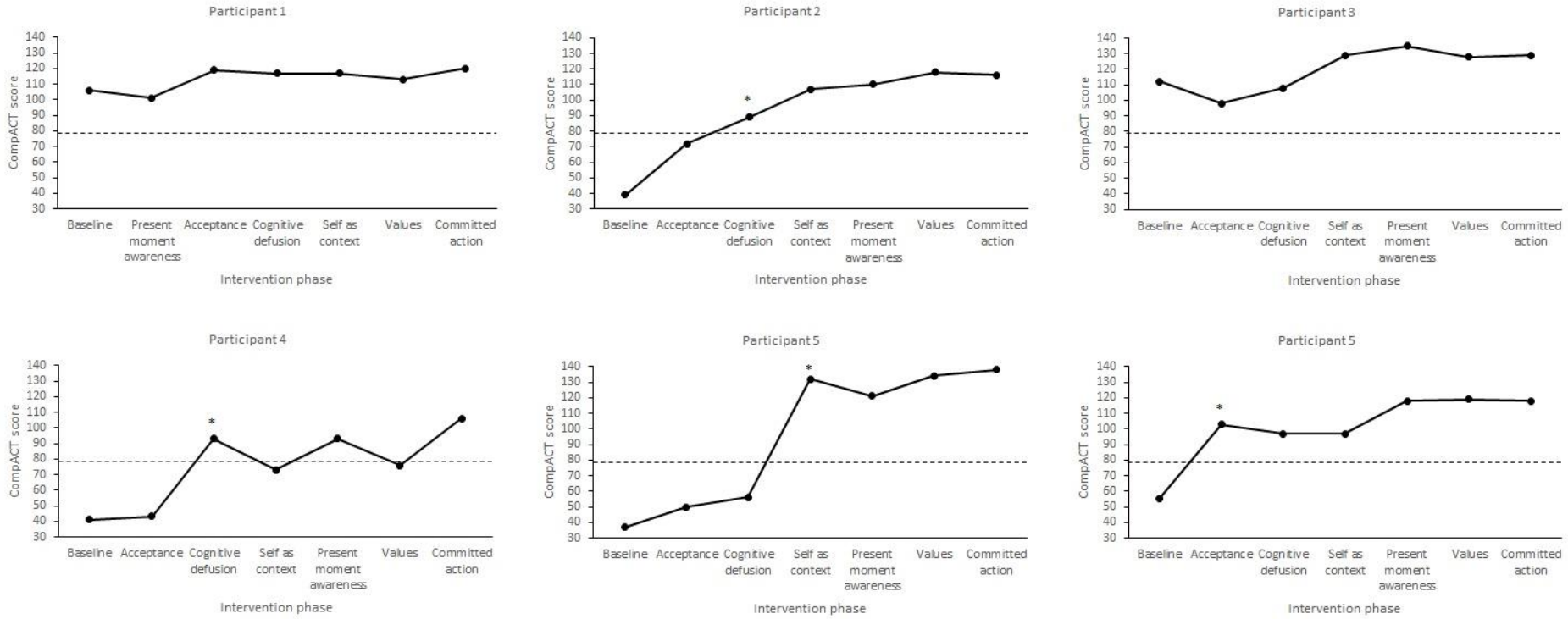
3.1.1 CompACT

In order to identify where changes occurred in terms of psychological flexibility for each participant, weekly participant scores on the CompACT were graphed. RCI and CSC were calculated for the CompACT using Jacobson and Truax's (1991) methodology and the data was inspected for any reliable or clinically meaningful change. Figure 26 displays the weekly responses on the primary psychological flexibility measure (Comprehensive Acceptance and Commitment therapy processes; CompACT) for each participant over the course of the intervention.

Four participants displayed reliable increases in psychological flexibility; P2 and P4 after the cognitive defusion phase, P5 following the self as context phase, and P6 after the acceptance phase. These changes were also deemed clinically significant at the time of reliable change for each participant. P1 and P3 did not show any reliable change during any of the intervention phases. All participants showed a continuing improvement in psychological flexibility after reliable changes had occurred, except for P4, whose psychological flexibility scores appeared to fluctuate between phases after a clinically and reliable change was observed.

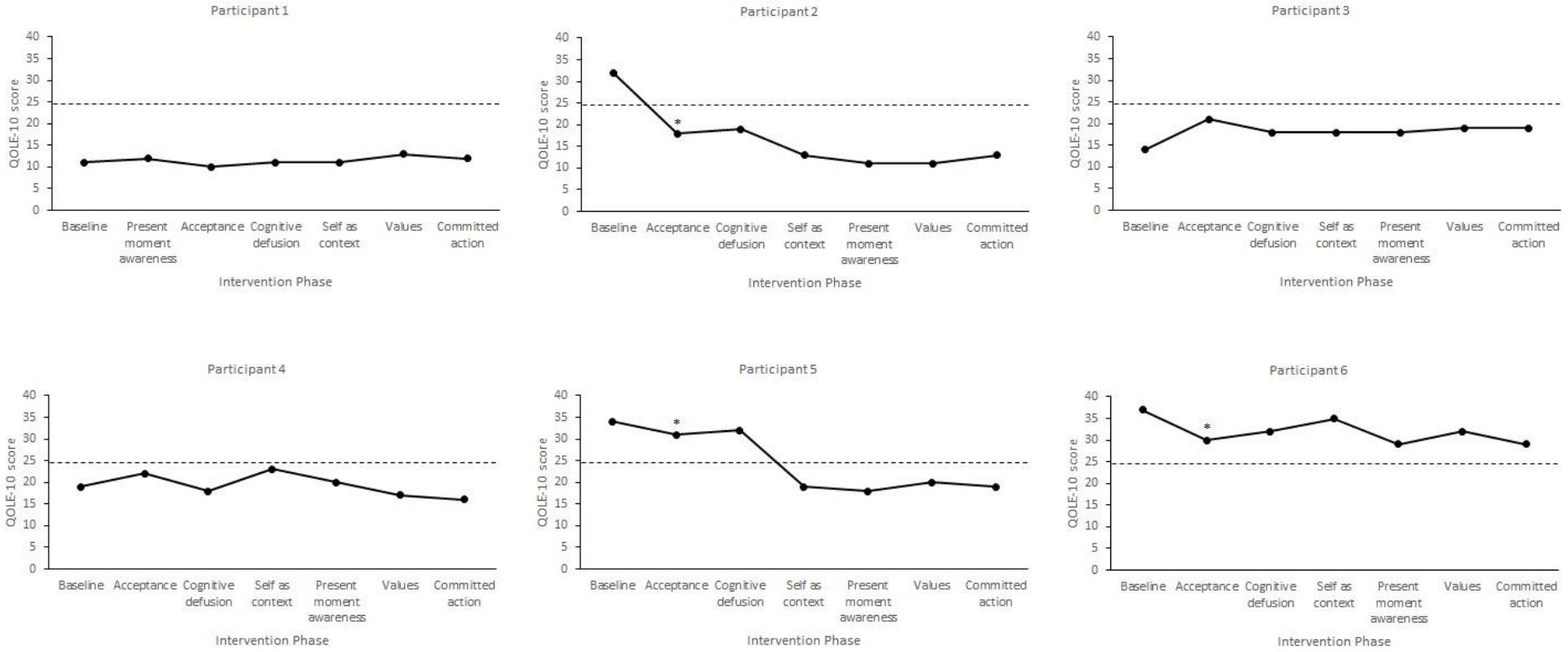
3.1.2 Quality of Life in Epilepsy scale

To determine at which points changes in quality of life occurred during the intervention, participant's weekly responses to the quality of life measure (QOLIE-10) were graphed. The data was also inspected for reliable and clinically significant change. Figure 27 illustrates the weekly quality of life scores for each participant.



Notes: direction of improvement is indicated by higher scores; CompACT=Comprehensive Acceptance and Commitment Therapy processes *= reliable change from pre-treatment score (i.e. change ≥ RCI value: 26.69); ------ = clinically significant cut-off at 79.59 (criterion c)

Figure 26. Weekly responses to the CompACT for each participant according to intervention phase



Notes: direction of improvement is indicated by lower scores; QOLIE-10= quality of life in epilepsy; *=reliable change from pre-treatment score (i.e. change ≥ RCI value: 1.49); ------ = clinically significant cut off at 24.90 (criterion c)

Figure 27. Weekly responses to the QOLIE-10 for each participant according to intervention phase

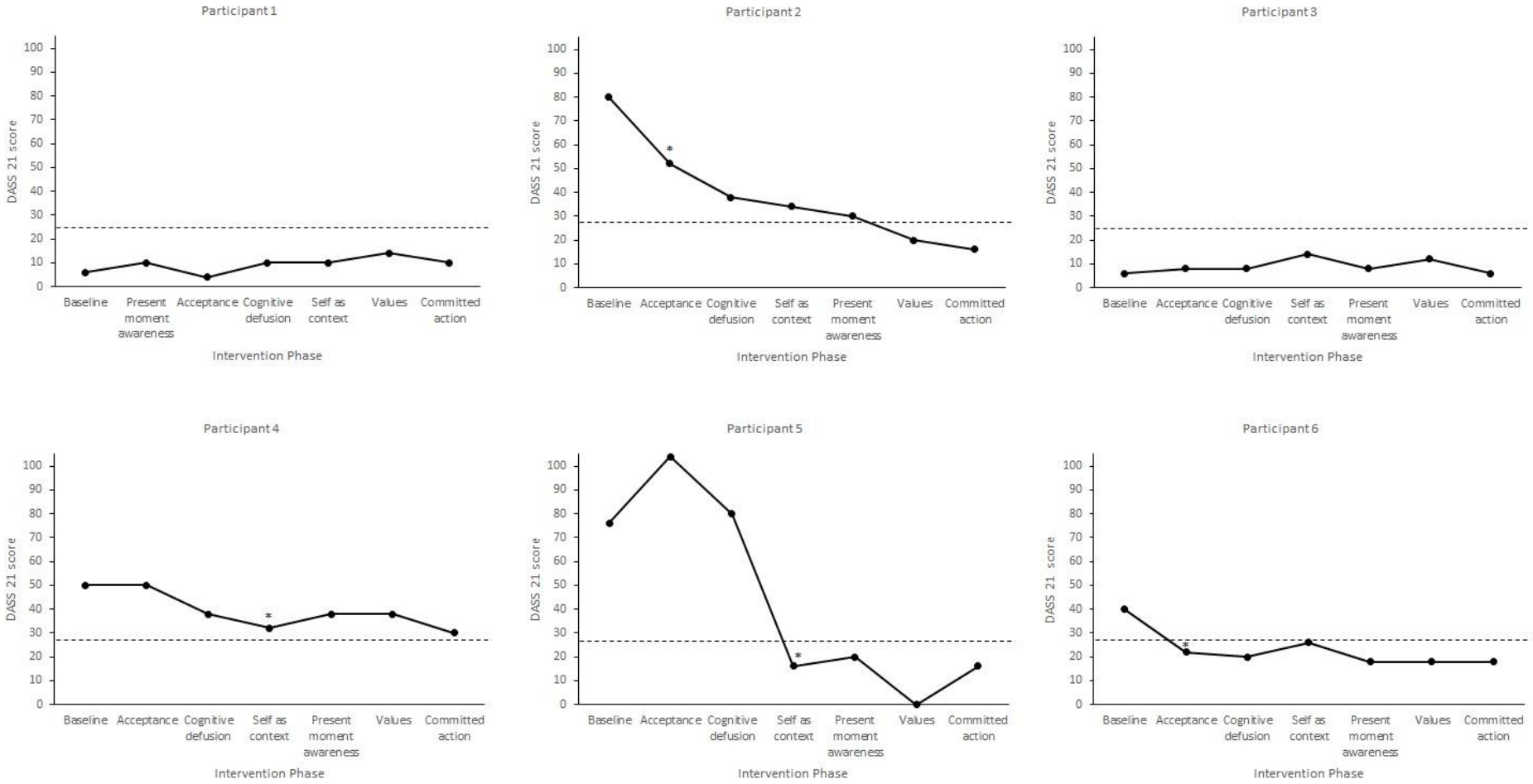
Three participants showed reliable improvements in their quality of life scores following the acceptance phase (P2, P5 and P6). P2's quality of life score reached clinically meaningful change at the same point of reliable change, whereas P5 showed clinically significant changes in quality of life following the self as context phase. P6 did not display any clinically significant changes. P1, P3 and P4 did not show any reliable changes in their quality of life scores throughout the intervention, however, it should be noted that P4's pre-treatment score was within the clinical range (P1 and P3 were not), therefore P4 shows a reliable and clinically significant score at baseline. As this change occurred after the baseline phase and before the intervention phase it could not be deemed a reliable change attributable to the intervention.

3.1.3 Depression Anxiety and Stress scale

To investigate whether there had been any changes in psychological distress for participants, reliable and clinically significant change was inspected on participant responses of the DASS 21 (an overall measure of psychological distress). Figure 28 displays the weekly responses of each participant on the DASS 21.

Four participants displayed a reliable improvement in psychological distress; P2 and P6 showed a reliable change following the acceptance phase, whereas reliable changes were identified for P4 and P5 after the self-as context phase. At the point of reliable change, two of the above participants displayed clinically significant changes (P5 and P6), P2 showed clinically reliable changes following the values phase, four weeks after the acceptance phase, however, P4 did not reach clinically significant levels of change until follow-up. P1 and P3's scores were not deemed as reliable as throughout the study their scores were within the non-clinical range for psychological distress[4].

[4] Note that participants were allocated to either the no burden group (P1 and P3) or the psychological burden group (P2, P4, P5 and P6) based on the normative data used for calculating RCI and CSC for a PNES population (Baslet et al., 2010).



Notes: direction of improvement is indicated by lower scores; DASS 21=depression anxiety & stress scale; *=reliable change from pre-treatment score (RCI value ≥14.03); ------= clinical cut off: 24.94 (P1 & P3); 28.39 (P2, P4, P5, P6) (criterion c)

Figure 28. Weekly responses to the DASS 21 for each participant according to intervention stage

3.1.4 Acceptance and Action Questionnaire

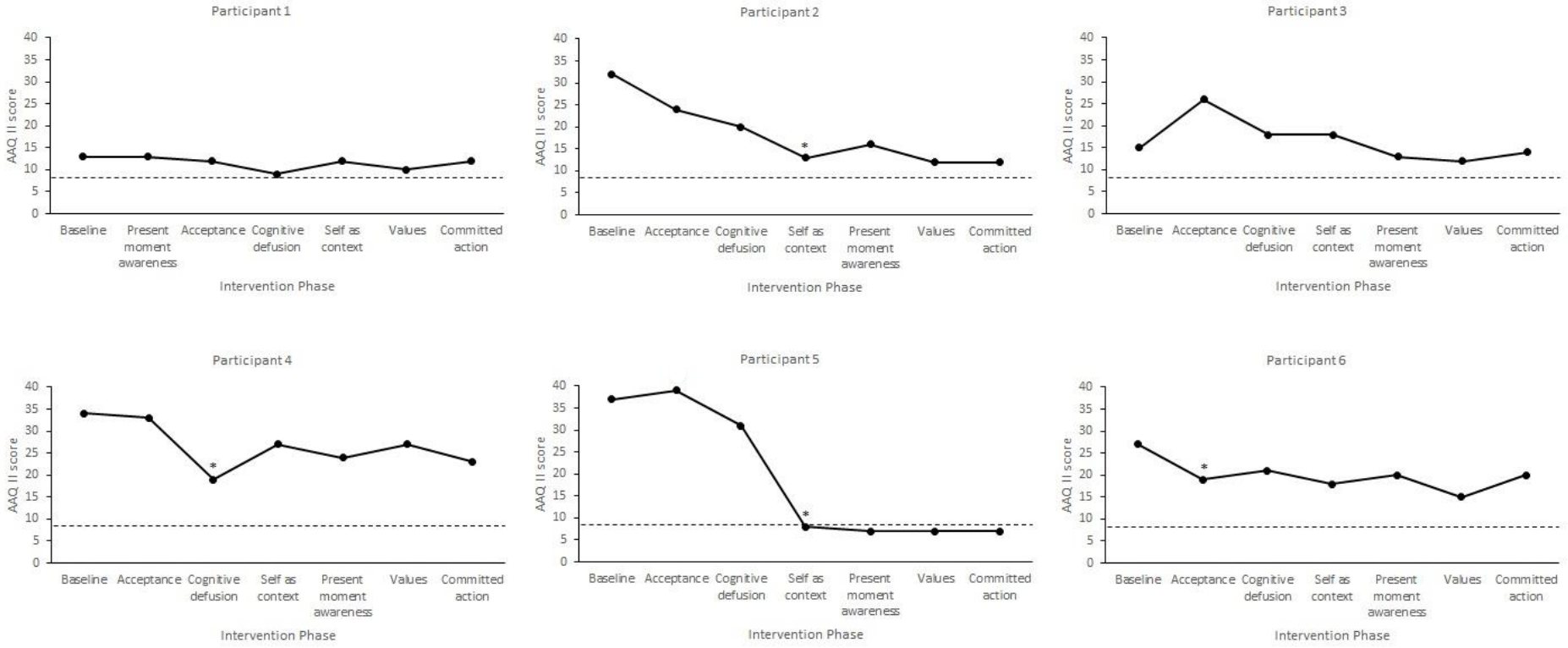
To determine whether changes occurred on the secondary measure of psychological flexibility (the Acceptance and Action questionnaire II; AAQ II), participants' weekly responses were graphed and RCI and CSC were calculated; again, using Jacobson and Truax's (1991) methodology. (See Figure 29)

P5 showed some deterioration in psychological flexibility after the acceptance phase, however, a reliable improvement was observed following the self as context phase. Reliable improvements were detected for three more participants; P2 improved following the self as context phase, P4 following the cognitive defusion phase, and P6 after the acceptance phase. P5 was the only participant that showed clinically significant changes on the AAQ II, which occurred after the self as context phase. P1 and P3 did not show any reliable or clinically significant changes during the intervention.

3.2 Analysis of the DASS-21 subscale measures

3.2.1 Pre, post and follow-up analysis of the Depression, Anxiety and Stress subscales

For the depression subscale, reliable and clinically significant changes were observed in four cases (P2, P4, P5 and P6), however, only 2 cases continued to reach clinical significance levels at the end of the one-month follow-up (P4 and P5). Three participants showed a reliable reduction in their *anxiety* (P2, P4 and P5) and these changes were also significant at the clinical level. Similarly, three cases showed reliable and clinically significant reductions in *stress* following the end of the study (P2, P3, and P5). P1 and P3 did not show any reliable changes in their depression, anxiety or stress scores and P6 only showed reliable and clinically significant changes in depression at post-treatment. (See Figure 30).



Notes: direction of improvement indicated by lower scores; AAQ II= acceptance and action questionnaire; *=reliable change from pre-treatment score (change ≥ RCI value: 8.95); ------=clinical cut off: 8.35 (criterion a)

Figure 29. Weekly responses to the AAQ II for each participant according to intervention stage

3.2.2 Weekly responses to the DASS 21 subscale measures

Weekly responses to the depression, anxiety and stress subscales from the DASS 21 were graphed and the data analysed to detect reliable and clinical change using RCI and CSC methodology (Jacobson & Truax, 1991).

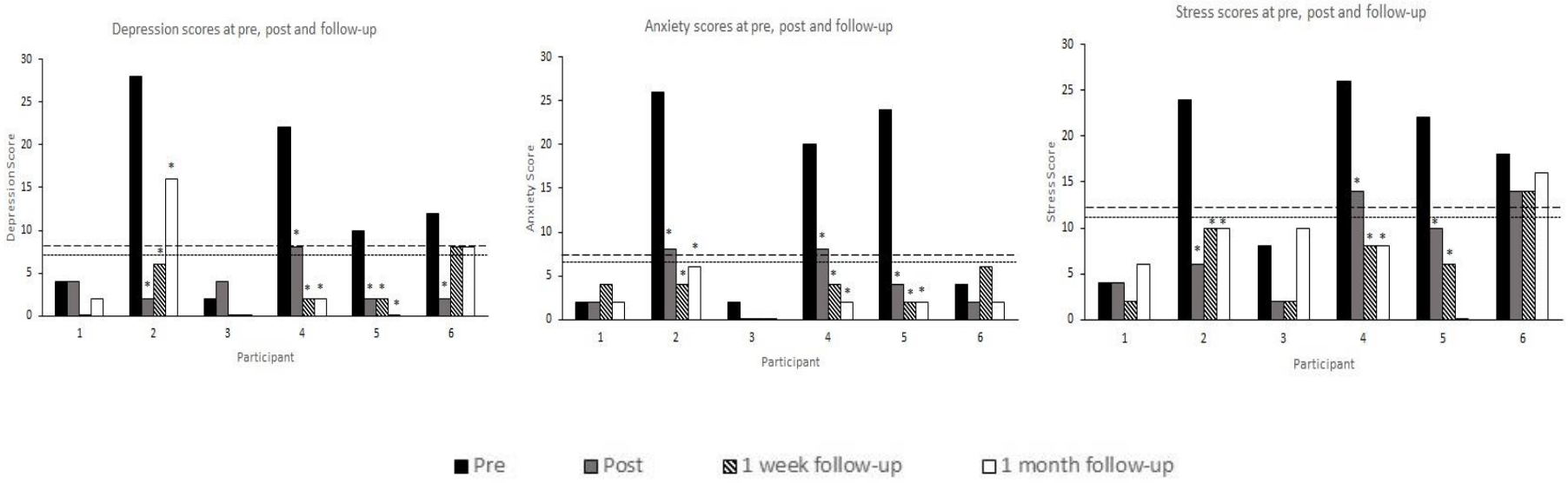
Figure 31 displays the weekly responses from participants on the depression subscale, Figure 32 displays responses on the anxiety subscale and Figure 33 displays responses on the stress subscale. RCI and CSC are calculated based on the normative data obtained from Baslet, Roiko and Prensky (2010), therefore participants were allocated into either the psychological burden group (P2, P4, P5 and P6) or the no burden group (P1 and P3).

3.2.2.1 *Depression*

Four participants displayed clinically reliable improvements in depression during the intervention. P2 and P6 showed clinically reliable change following the acceptance phase and P5 displayed clinically reliable change following the self as context phase. A reliable change was observed in P4's depression after the values phase, but clinically significant levels of change were not observed until after the next phase; committed action. P1 and P3 did not show any reliable changes in depression at any point during the intervention.

3.2.2.2 *Anxiety*

Reliable changes were detected for anxiety in three participants; P4 and P5 following the self as context phase and P2 following the cognitive defusion phase. P4's changes were also clinically significant at the point at which reliable change occurred, however, P2 and P5 did not display clinically significant changes until several phases after reliable change had occurred; for P2, this was not until the values phase and for P5 clinically significant changes were observed immediately after the present moment awareness phase. No reliable changes were observed for P1, P3 or P6 in relation to their anxiety and remained within the non-clinical range throughout the study, except for P1, where an increase in anxiety was observed after the values phase, however, this change was not deemed reliable.



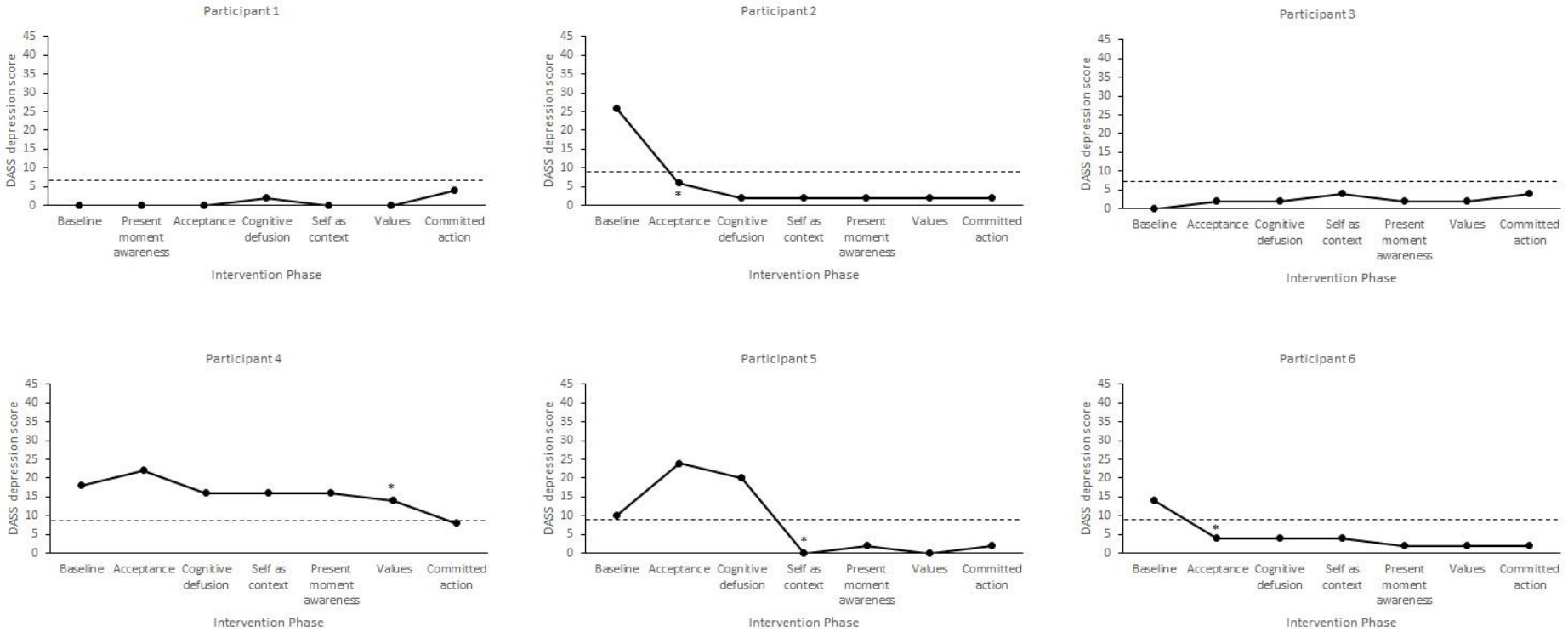
Notes: Participants were allocated to either a "no burden" (NB) group or "psychological burden" (PB) group to calculate RCI and CSC, based on normative data obtained for a PNES population (Baslet et al., 2010). P1 and P3 were allocated to the NB group; P2, P4, P5 and P6 were allocated to the PB group.

------ PB clinical cut off (criterion c) = 8.53 (depression), 11.83 (anxiety), 6.83 (stress)*;* *=PB reliable change ≥ 6.20 (depression), 11.83 (anxiety), 6.83 (stress); ····· NB clinical cut off (criterion c) = 7.36 (depression), 6.55 (anxiety), 10.96 (stress)*;* *=NB reliable change ≥ 9.41 (depression), 6.55 (anxiety), 8.01 (stress)

Figure 30. Bar chart showing depression, anxiety and stress (DASS 21 subscale) outcomes

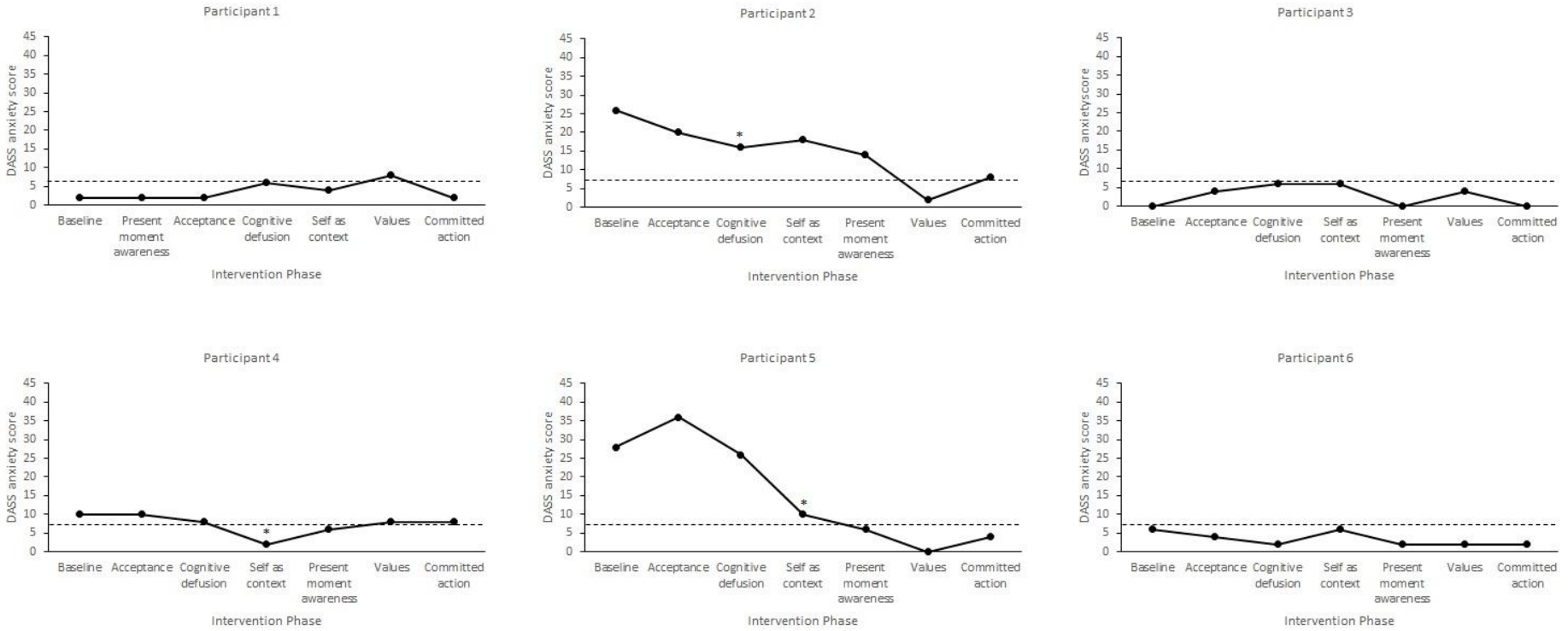
3.2.2.3 *Stress*

Reliable change in stress scores were detected in three participants during the intervention; P2 and P4 after the cognitive defusion phase and P5 following the self as context phase. P5 also displayed clinically significant change at the point of reliable change, whereas P2's changes were not deemed clinically significant until after the committed action phase (4 phases after reliable change was detected). P4's changes did not reach clinically significant levels during the rest of the intervention; however, this was detected at follow-up (see extended paper 3.3.1). No reliable changes in stress were detected for the remaining three participants; P1 and P3 remained within non-clinical levels throughout the intervention, whereas P6 did not show any reliable changes in stress scores and remained within the clinical range.



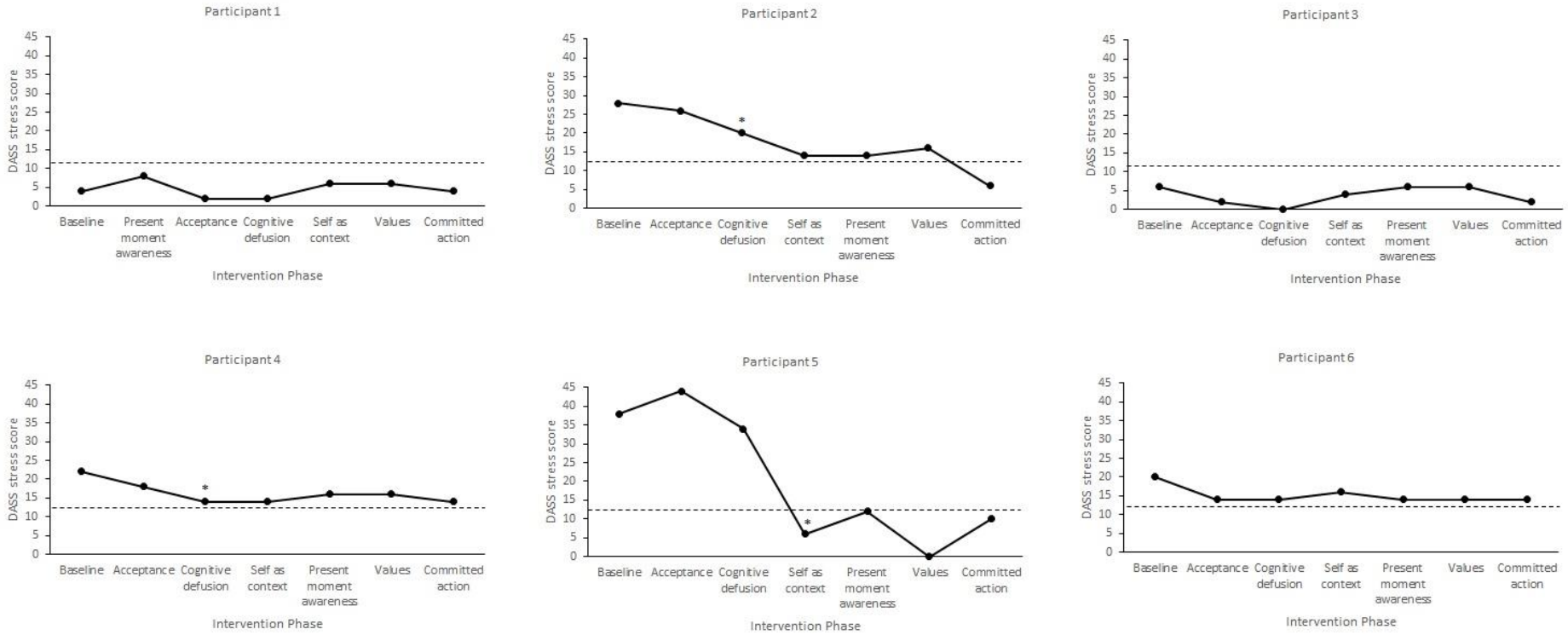
Notes: improvement indicated by lower scores;
P1 and P3= no burden group (NB); *=reliable change from pre-treatment score (change ≥ RCI value: 9.41); ------=clinical cut off: 7.36 (criterion c)
P2, P4, P5 and P6= psychological burden group (PB); *=reliable change from pre-treatment score (change ≥ RCI value:6.20); ------=clinical cut off: 8.53 (criterion c)

Figure 31. Responses capturing depression (DASS 21– depression subscale) for each participant according to intervention phase



Notes: improvement indicated by lower scores;
P1 and P3= no burden group (NB); *=reliable change from pre-treatment score (change ≥ RCI value: 6.55); ------=clinical cut off: 6.55 (criterion c)
P2, P4, P5 and P6= psychological burden group (PB); *=reliable change from pre-treatment score (change ≥ RCI value:11.83); ------=clinical cut off: 7.38 (criterion c)

Figure 32. Responses capturing anxiety (DASS 21– anxiety subscale) for each participant according to intervention phase



Notes: improvement indicated by lower scores;
P1 and P3= no burden group (NB); *=reliable change from pre-treatment score (change ≥ RCI value: 8.01); ------=clinical cut off: 10.96 (criterion c)
P2, P4, P5 and P6= psychological burden group (PB); *=reliable change from pre-treatment score (change ≥ RCI value:6.83); ------=clinical cut off: 12.10 (criterion c)

Figure 33. Responses capturing stress (DASS 21– stress subscale) for each participant according to intervention phase

3.3 Analysis of weekly ACT process measures

Three ACT processes, as measured by the CompACT subscales, of openness to experience (OE), behavioural awareness (BA) and valued action (VA) were inspected for change across the intervention phases of the study to identify where change occurred for each participant. As such, participants' weekly responses to each process was graphed and the data was analysed for reliable and clinically significant changes using RCI and CSC methodology (Jacobson & Truax, 1991)

Figure 34 displays weekly participant responses to the OE processes, Figure 35 displays weekly participant responses to the BA processes, and Figure 36 displays weekly participant responses to the VA processes.

3.3.1 Openness to Experience

Four participants showed reliable change during the intervention for the OE processes; P2 and P4 following the cognitive defusion phase, P5 following the self as context phase, and P6 following the acceptance phase. Furthermore, all changes were deemed clinically significant at the same point in which reliable change occurred. P1 and P3 did not display any reliable changes during the intervention related to OE, as all their scores fell within the non-clinical range.

3.3.2 Behavioural Awareness

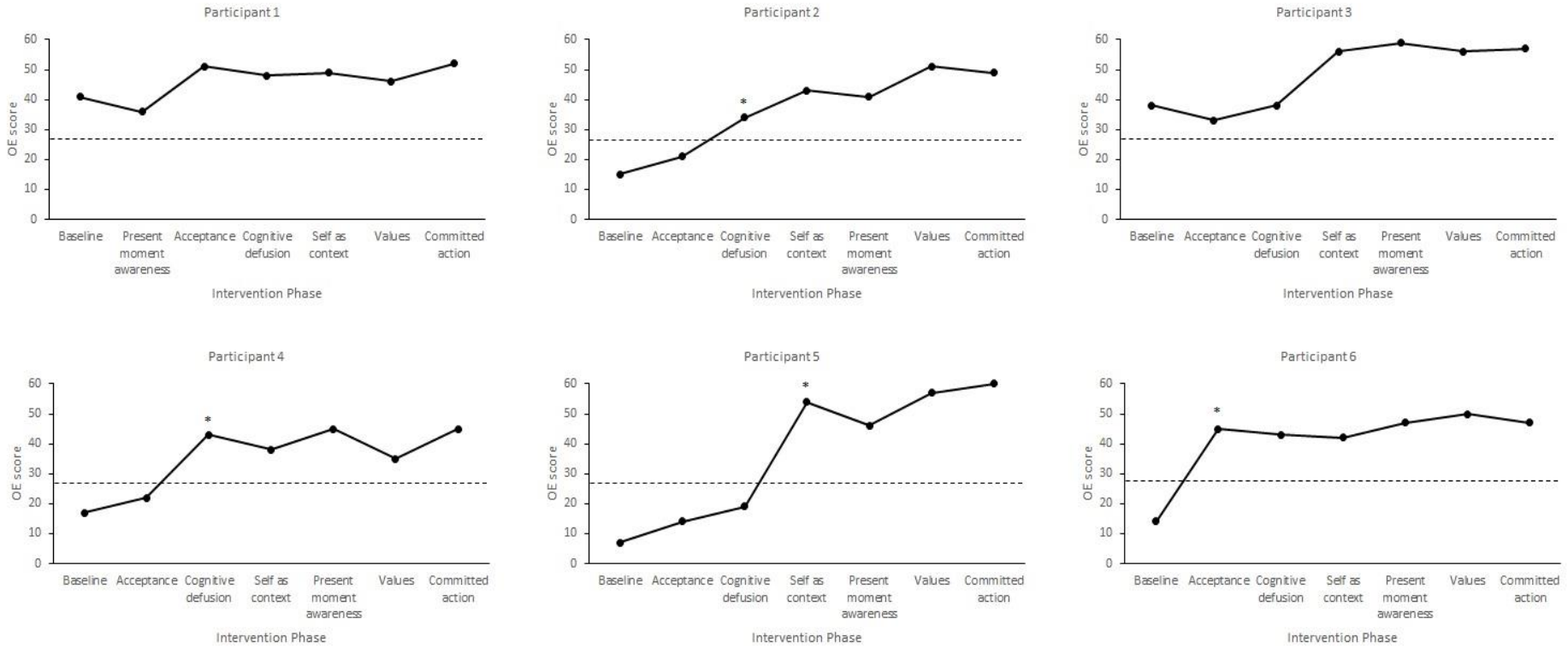
In relation to the BA processes, four participants displayed reliable changes during the intervention; P2 and P6 after the acceptance phase, P4 after the cognitive defusion phase, and P5 after the self as context phase. All participants who made reliable changes were deemed clinically significant at the point of which reliable change was observed. After reliable and clinically significant change had been observed, these scores continued to rise throughout the rest of the intervention for P2 and P5. P6 showed a slight deterioration in scores following the cognitive defusion phase, however, BA appeared to rise again and stabilise following the present moment awareness phase. P4's scores of BA appeared to fluctuate between clinical and non-clinical ranges after reliable

change was observed but appeared to rise back to the non-clinical range following the valued action phase. P1 and P3's BA scores were within the non-clinical range throughout the intervention, therefore any changes could not be deemed as reliable.

3.3.3 Valued Action

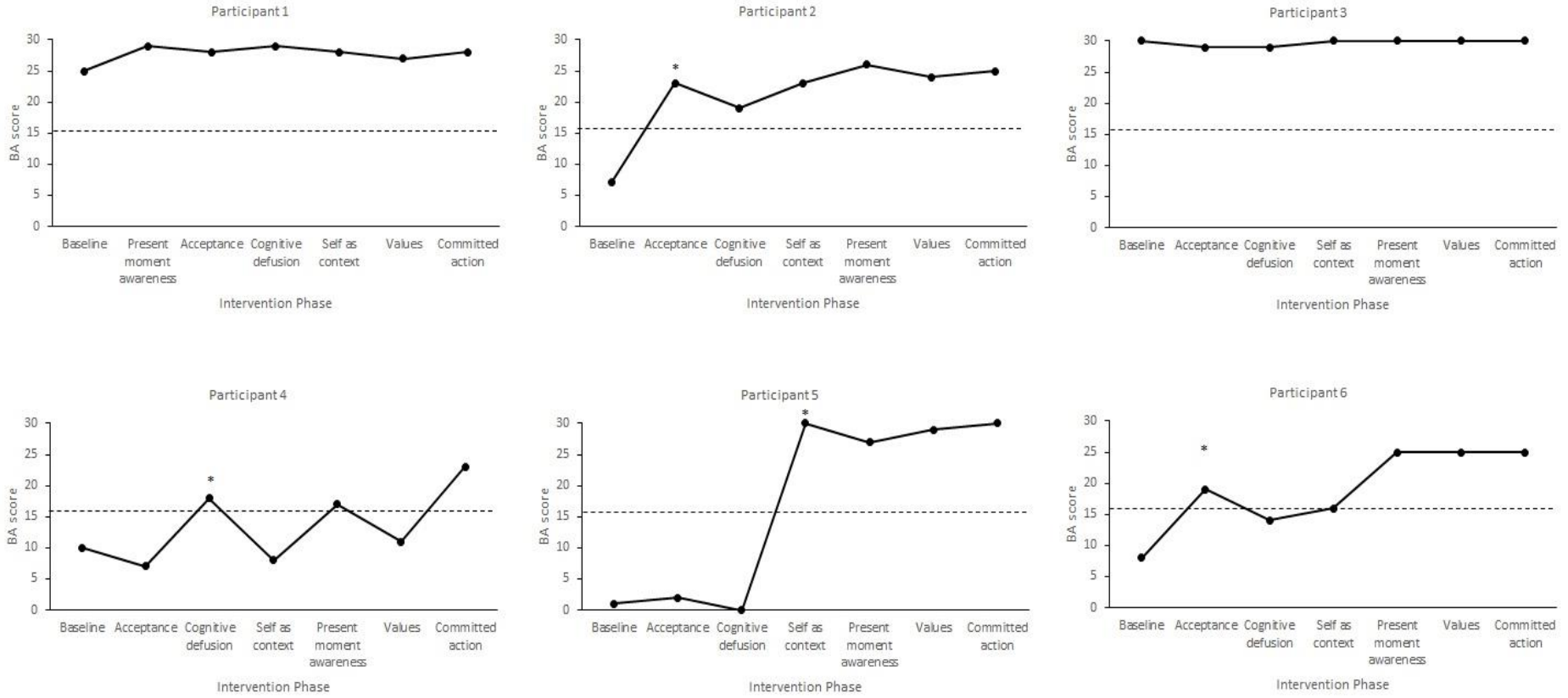
Four participants displayed reliable changes in VA processes; P2 and P4 showed reliable change after the cognitive defusion phase, P5 after the self as context phase, and P6 following the present moment awareness phase. Clinically significant change was also observed for four participants; P2 at the same point of reliable change and P4 following the committed action phase (and four phases after reliable change was observed). P5's VA scores were within the non-clinical range following the cognitive defusion phase, however the change was not deemed reliable until after the self as context phase. Similarly, P6's VA scores fell within the non-clinical range following the acceptance phase, but this was not deemed a reliable change until after the present moment awareness phase.

P1 and P3 did not show any reliable changes in BA; their scores remained within the non-clinical range throughout the study.



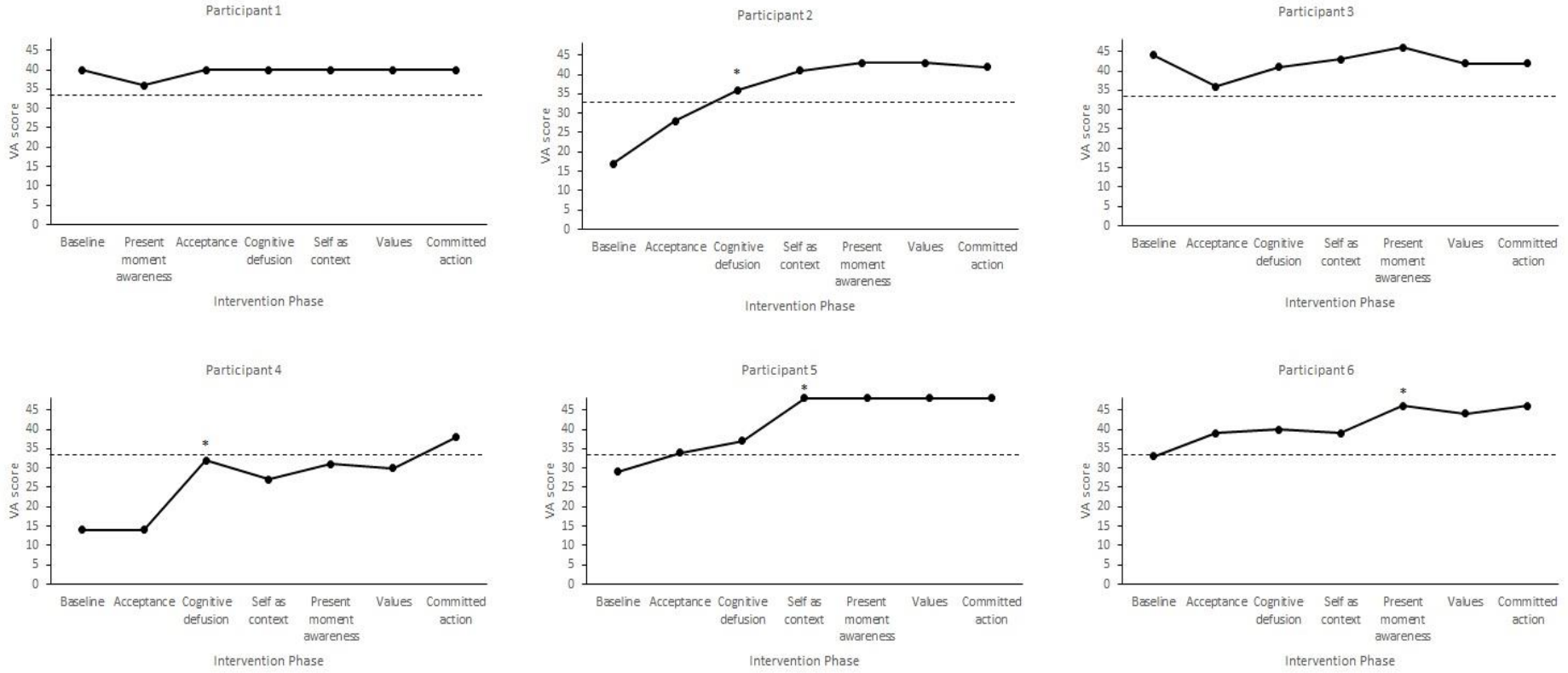
Notes: direction of improvement indicated by higher scores; Openness to experience = OE; *= reliable change from pre-treatment score (change ≥ RCI value:13.6); ------= clinical cut off: 28.29 (criterion c)

Figure 34. Responses to the ACT processes capturing acceptance and cognitive defusion (OE- CompACT subscale) for each participant according to intervention phase



Notes: direction of improvement indicated by higher scores; Behavioural awareness=BA; *= reliable change from pre-treatment score (change ≥ RCI value:10.63); ------= clinical cut off: 15.44 (criterion c)

Figure 35. Responses to the ACT processes capturing self as context and present moment awareness (BA-CompACT) subscale for each participant according to intervention phase



Notes: direction of improvement indicated by higher scores; Valued action=VA; *= reliable change from pre-treatment score (change ≥ RCI value:7.31); ------= clinical cut off: 34.52 (criterion c)

Figure 36. Responses to the ACT processes capturing values and committed action (VA-CompACT subscale) for each participant according to intervention phase

3.4 Overall synthesis of weekly ACT processes

Reliable changes related to the target ACT processes of openness to experience (acceptance and cognitive defusion) were detected in congruence with or immediately following the relative treatment phase for three participants; that is, reliable changes in openness to experience were observed during the first two treatment phases (P2, P4 and P6). A reliable change was detected in the process capturing openness to experience for another participant, however, this was not until after the third treatment phase (P5). P1 and P3 showed no reliable improvements on the openness to experience process.

In relation to the second ACT process of behavioural awareness (self as context and present moment awareness), reliable changes were detected in the target ACT process during the third and fourth treatment phase for one participant (P5; self as context phase). No other participants displayed initial reliable changes in behavioural awareness during the target treatment phases, however, reliable changes were detected in the phases preceding them (P2, P4 and P6). Nonetheless, increases in behavioural awareness were observed following the present moment awareness phases for P2, P4 and P6. P1 and P3 showed no reliable improvements on the behavioural awareness process.

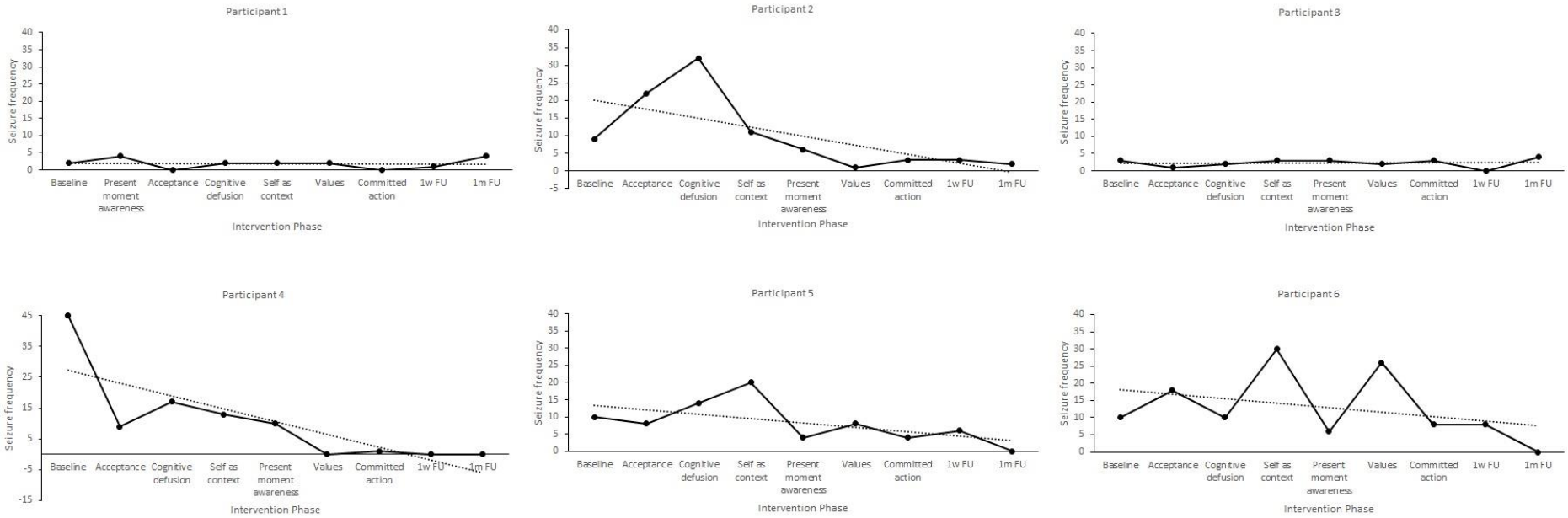
The target ACT process of valued action (values and committed action processes) was detected as a clinically significant improvement in just one participant during the last two treatment phases (values and committed action), which occurred immediately after the committed action phase (P4). Reliable changes were observed in valued action processes for a further three participants, although initial changes were observed during the behavioural awareness treatment phases (P5 and P6) and the acceptance phase (P2). Valued action appeared to rise following the values treatment phase for P2, however, for all other participants, there did not appear to be any further impact on the valued action process following the values and committed action phases. Similar to the above findings, P1 and P3 again showed no reliable changes in valued action, irrespective of any of the treatment phases.

When considering all the ACT process measures together, intervention phase that appeared to attribute the most frequent shifts in reliable change was the cognitive defusion phase, closely followed by both the acceptance and self as context phases; this suggests that openness to experience is an important process which, in addition, may aid the development of other ACT processes, including behavioural awareness and valued action. Furthermore, the frequency of reliable shifts during the first three treatment phases suggest that these are potentially the most influential processes in improving psychological flexibility.

3.5 Weekly seizure frequencies

RCI and CSC could not be calculated for seizure frequency, however, Figure 37 displays the number of seizures reported for each participant within each treatment phase. Visual inspection of the graphed data illustrates that all participants either experienced a stable trend in the frequency of their seizures throughout the study, or a declining trend in the frequency of the seizures. P1 and P3 did not show any changes in the frequency of their seizures throughout the study, displayed by a stable trend line. P2, P4, P5 and P6 all show a decrease in the frequency of their seizures during the treatment phase.

P2, P5 and P6 experienced a peak in the frequency of seizures within the first three treatment phases: P2 during the cognitive defusion phase, and P5 and P6 during the self as context phase. However, following this peak in seizure frequency, a rapid reduction in seizure frequency was reported following the next treatment phases, which continued up until follow up for P2 and P5. P6's reported seizure frequencies fluctuated between phases following the initial peak, however, appeared to stabilise at the end of the study through till follow-up. P4 appeared to have experienced the most dramatic reduction in seizure frequency during the acceptance phase, which continued to decrease further during the values phase through to follow-up.



Notes: graphs indicating number of seizures following intervention phase – not all frequencies are equal to one week: see time series analysis graphs/journal paper for length of treatment phase per participant; 1w FU=one-week follow-up; 1m FU=one-month follow-up; ·····= trend line

Figure 37. Reported seizure frequency for each participant according to intervention phase

3.6 Results summary for each participant

The following section presents a narrative of the overall results for each participant during the study and in relation to all measures used. Please refer to the journal paper and previous sections of the extended paper for tabulated and/or graphed results.

3.6.1 Participant 1 (P1)

P1 did not show any reliable changes on any of the measures except for the measure of valued action (VA) at follow-up. Upon closer inspection of these results and regarding the weekly treatment phases, it appeared that the change occurred during the baseline phase; therefore, changes in VA could not be attributed to a specific intervention phase of the study. It is possible that upon beginning the study a Hawthorne effect took place, in which case, his scores may have improved as a result of the knowledge that he was being observed. However, no reliable changes were observed in any of the other domains, although this is due to P1 falling within the non-clinical range for all other measures, apart from on the AAQ. In relation to the AAQ II, no reliable changes were reported, however the largest improvement in this score was reported following the cognitive defusion treatment phase.

In relation to seizure frequency, P1 reported low level seizure frequency during the baseline phase and throughout the study, therefore, the changes reported were minimal. The intervention did not appear to have any reliable impact on P1's quality of life, overall psychological distress, seizure frequency or psychological flexibility, however, the effectiveness of the intervention in raising psychological flexibility was reported as being moderately effective.

3.6.2 Participant 2 (P2)

Reliable changes were detected on all measures for P2, furthermore, all changes were clinically significant at some point during the study, except for reporting clinically significant changes on the AAQ II. Inspecting the reliable changes in relation to the treatment phases, it appeared that reliable changes in

quality of life, overall psychological distress, depression and behavioural awareness occurred following the acceptance phase and were also reported as clinically meaningful; the only exception was related to overall psychological distress, whereby a reliable change from the clinical range to non-clinical range was observed immediately after the values phase. Reliable improvements in psychological flexibility (as measured by the CompACT), anxiety, stress, openness to experience and valued action reportedly occurred following the cognitive defusion treatment phase where changes were also deemed clinically significant bar two cases; clinically significant change was observed in anxiety following the values phase and in stress following the committed action phase. A reliable change was seen in the AAQ II (measuring psychological flexibility) following the self as context phase, however this change did not reach clinically significant levels.

The overall treatment effect of raising psychological flexibility was deemed to be moderately effective using Ma's (2006) percentage exceeding the median (PEM) method. Furthermore, although not a primary aim of the study, P2's seizure frequency reduced by more than half by the end of the one-month follow-up. A reduction in the trend for frequency of seizures appeared following the self as context intervention until the end of the study.

3.6.3 Participant 3 (P3)

P3 displayed an improving trend on all the measures, however no reliable changes were reported during any part of the study. Although improvements were noted in quality of life, overall psychological distress, and overall psychological flexibility, these changes were not deemed as reliable as P3 scored within the non-clinical range on all measures, except for the AAQ II, prior to beginning the baseline phase of the study. Therefore, it is not surprising that the effectiveness of the study was found as "not effective" in raising psychological flexibility using the PEM method. Furthermore, no changes were observed in seizure frequency throughout the study, although the qualitative subjective feedback suggested that P3 is "more aware of [her] thoughts and generally feeling better", which may reflect the improving trends in quality of life, psychological flexibility and psychological distress. P3 reported that the

openness to experience chapters of the intervention were the most influential, however, this was not reflected when calculating reliable and clinically significant changes in relation to the treatment phases.

3.6.4 Participant 4 (P4)

P4 reported reliable changes immediately following the cognitive defusion phase in psychological flexibility (as measured by both the CompACT and AAQ II), stress, openness to experience, behavioural awareness and valued action. In all of the above cases (except on the AAQ II and stress), these changes were also deemed clinically significant following the cognitive defusion phase (AAQ II and stress scores did not reach clinically significant levels). A reliable change in overall psychological distress and anxiety was observed after the self as context phase; clinically meaningful changes were also observed following this phase in anxiety, however, for overall psychological distress, these changes were not deemed significant at a clinical level. A reliable improvement in depression scores was observed following the values phase, although it was only deemed clinically significant following the next treatment phase.

Inspection of the weekly responses the quality of life measure illustrate that no reliable or clinically significant changes occurred during the intervention, however, at follow-up, P4 reported both reliable and clinically significant changes. Closer inspection of the weekly responses and pre and post results show that a reliable improvement occurred during the baseline phase; however, as no intervention was delivered during the baseline, another factor will need to account for the changes reported here. A possible Hawthorne Effect[5] may have impacted the quality of life results as the baseline data shows quality of life within a non-clinical range, whereas the screening results display quality of life within the clinical range.

In terms of the treatment effectiveness, the treatment was deemed as highly effective in raising psychological flexibility for P4, as calculated using PEM

[5] The Hawthorne Effect is the change in behaviour as a result of being observed (McCambridge et al., 2014)

methodology. Furthermore, a dramatic reduction in seizure frequency was observed at one-month follow-up, where no seizures were reported; prior to that, a reduction in seizures was reported following the self as context phase and continued to decrease for the remainder of the study period.

3.6.5 Participant 5 (P5)

Reliable and clinically significant change was detected on all measures for P5. The most influential treatment phase appeared to be self as context, as the majority of reliable and clinically significant change was detected immediately following this treatment phase. Reliable and clinically significant change following the self as context phase occurred in: psychological flexibility (as measured by both the CompACT and AAQ II), overall psychological distress, depression, stress, openness to experience and behavioural awareness. Reliable changes were reported in anxiety following the self as context phase, however, clinically significant changes were not observed until after the present moment awareness phase (although one could argue that both these intervention phases are part of the behavioural awareness process). P4 also reported a reliable change in quality of life, which occurred following the acceptance phase, although clinically significant changes were observed following the self as context phase. The only measure in which self as context was not influential in detecting reliable or clinically significant change was valued action; for this process, P5 reported reliable change immediately after the present moment awareness phase, although clinically significant levels were observed prior to reliable changes, during the acceptance treatment phase. Furthermore, seizure frequency appeared to decline following the present moment awareness phase and continued to decline throughout the remainder of the study; P5 also reported an absence of seizures in the week preceding the one-month follow-up, this was corroborated with qualitative feedback at the time of the change interview, where she stated that she had not experienced any seizures for the past three weeks.

Given that P5 was the only participant to make clinically reliable changes on *all* outcome measures, it is surprising that the impact of the intervention was

deemed “not effective” in raising psychological flexibility according to Ma's (2006) PEM method.

3.6.6 Participant 6 (P6)

P6 reported reliable changes in psychological flexibility (measured by both the CompACT and AAQ II), quality of life, overall psychological distress, depression, openness to experience, behavioural awareness and valued action. The most influential treatment phase in for both reliable and clinically significant change appeared to be the acceptance phase: reliable and clinically significant changes occurred following this phase for psychological flexibility (measured by the CompACT), overall psychological distress, depression, openness to experience and behavioural awareness. Reliable but not clinically significant changes occurred in both the quality of life measure and the AAQ II following the acceptance phase. The only reliable change that was not preceded by the acceptance phase was on the measure of valued action, where reported reliable change occurred after the present moment awareness phase, although clinical significant changes were observed during the acceptance phase for this process. No reliable or clinically significant changes were reported on the measures of anxiety or stress as P6’s pre-treatment scores were already within the non-clinical range. In relation to quality of life, these changes remained reliable at follow-up, but were not within the non-clinical range, and her scores at follow-up for overall psychological distress remained within the non-clinical range, however, were no longer deemed as reliable changes from her pre-treatment score.

The PEM method was applied to P6’s data to evaluate the overall effectiveness of the intervention in raising psychological flexibility and was found to be “highly effective”. Furthermore, P6 reported experiencing no seizures at the one-month follow-up and closer inspection of the weekly seizure frequency data indicate that seizures appeared to reduce consistently following the committed action phase.

4 Extended Discussion

4.1 P1 and P3

The participants that demonstrated no clinically meaningful change on the study outcomes may reflect the low levels of distress they experienced prior to starting the study and therefore an ACT intervention may be more beneficial for those with higher reported levels of distress and reduced quality of life. However, even in these cases, psychological flexibility appeared to increase throughout the study and were higher at follow-up than they had been at pre-treatment. As no other changes were observed, it is possible that the increase in psychological flexibility reflected a socialisation to the ACT model and ACT language, rather than psychological flexibility increasing as a direct result of the intervention.

Both P1 and P3 scored within a 'functional range' on all of the outcome measures (except on the AAQ -II; the limitations of the AAQ II have been described in section 2.3.5 of this paper). As a result, although increases were observed in all outcomes, these could not be deemed as reliable when using RCI/CSC methodology. However, individuals with PNES may underreport symptoms of psychological distress (Binzer et al., 2004; Stone et al., 2015), which may explain why initial outcome scores fell within a 'functional' range, but also provides a rationale as to why P1 and P3 came forward to participate in the study; although distress and quality of life scores appeared to be unaffected by PNES, it was assumed that there must have been something about seizures motivating them to seek help, even if they were unable to recognise this overtly. Furthermore, P1 and P3 reported no change in the frequency of their seizures, and although this was not a primary outcome of the current study, other participants that did make reliable changes in psychological flexibility reported fewer and no seizures following the end of the intervention, suggesting that reliable increases psychological flexibility impact on seizure frequency. Therefore, it is possible that a 'higher dose' of the ACT intervention, such as formal 1:1 therapy, which was beyond what a self-help intervention could offer,

may be beneficial for patients that underreport psychological symptoms but still seek support,

4.2 Findings in context of extant research and theory

4.2.1 Cognitive-behavioural

A CBT approach offers an account of how a particular way of thinking can mediate emotions and behaviour; catastrophising (thinking something is worse than it really is), dichotomous thinking ("all or nothing" thoughts), jumping to conclusions (mind reading) and rumination/worry are some examples of the 'thinking styles' often observed within general psychopathology (Wells, 2011). Evidence from medically unexplained symptoms (MUS) studies demonstrates an association between catastrophisation and somatisation (Rief et al., 1998), in which catastrophisation mediates the development of stress symptoms following a traumatic event (Bryant & Guthrie, 2007). Furthermore, worry or rumination, coupled with negative interpretation of symptoms, may lead to avoidant behaviour (Wells, 2011). The assumption that individuals with PNES exhibit similar thinking styles to those with general psychopathology and MUS has implications for the current study.

It is natural to assume that individuals with PNES experience greater levels of anxiety in anticipation of seizures. The relationship between seizures and anxiety may reflect rumination/worry, hypervigilance to threat and/or catastrophisation, leading to avoidance (Goldstein & Mellers, 2006; Vlaeyen et al., 1995), which has been discussed in detail in the introductory sections of this paper. The effectiveness of CBT approaches in treating PNES may arise from the successful application of cognitive restructuring techniques in which reappraisals of unhelpful thinking patterns mediate changes in emotions and behaviour, hence, interrupting the maintenance cycle of fear, anxiety and avoidance (Goldstein, Chalder, et al., 2010; LaFrance Jr., 2005; LaFrance Jr. et al., 2009).

Cognition (including thoughts, beliefs, expectations etc.) appears to be an important aspect in treating people with PNES, as they function to limit the type and frequency of activities engaged in. Both CBT and ACT work with thoughts, albeit in seemingly different ways which appears to lead to amelioration in both seizure frequency and associated psychosocial difficulties. In the current study, it appeared that acceptance/cognitive defusion and to some extent, self as context, were the most influential aspects of the therapy. From an ACT perspective, this would have involved participants being open to the direct experience of painful thoughts, feelings, urges and sensations instead of suppressing them and the paradoxical experience of allowing 'unhelpful' thoughts into awareness appeared to alleviate symptoms of distress (Hayes et al., 1999). Hayes et al. (1999) argues that acceptance is a distinct process from cognitive restructuring, where the focus on thought content and labelling thoughts as 'faulty' increases the desire to supress them. Conversely, cognitive reframing (a core approach within cognitive restructuring) appears to reduce the expression of negative emotion without the ineffective consequences of suppression (Gross, 2002). Furthermore, it can be argued that cognitive restructuring, like acceptance, demands direct confrontation with previously suppressed material through thought challenging and monitoring; in other words, cognitive restructuring enhances exposure to suppressed cognitions (Arch & Craske, 2008).

Within the current study, it appeared that the development of acceptance-based strategies led to ameliorative change in the majority of participants and may be seen as a key mechanism for change in PNES. The findings of the study also have implications for CBT, as the approach may share more similarities with ACT than differences, then this may provide useful information in the possible mechanisms of change active in the successful application of CBT treatments for PNES. Although more research is needed to examine the mechanisms of change in both CBT and ACT for PNES in order to further support this claim, the paradoxical benefits of being open to previously painful and supressed experiences is promising for future treatment.

4.2.2 Experiential avoidance

Findings from the current study demonstrate that the ACT intervention led to an increase in acceptance, which converged with improvements in quality of life, psychological distress and seizure frequency for the majority of participants. The final change interview also demonstrated that participants had engaged in activities they had previously avoided as a result of their seizures; this included going out in public, going on holiday, repairing a musical instrument in a public place, and painting and decorating; one participant also started working more days. Although the current study did not include behavioural tests to measure engagement in previously avoided activities, it appeared that participants did demonstrate a willingness to engage in such activities and the intervention facilitated engagement in these areas. Furthermore, experiential avoidance has been described as a key contributing factor in PNES (Baslet & Hill, 2011; Dimaro et al., 2014; Goldstein & Mellers, 2006) and the current study supports these findings. Critically, an ACT guided self-help intervention targets experiential avoidance for PNES through the development of acceptance-based strategies; this appeared to be highly beneficial for participants that initially reported high levels of psychological distress and inflexibility. Furthermore, increases in acceptance and willingness preceded values-based action, suggesting that targeting experiential avoidance is important in treating individuals with PNES.

4.3 Further limitations and strengths

4.3.1 Sampling considerations

4.3.1.1 *Recruitment Process*

As participants were recruited from non-clinical settings (i.e. social media Facebook groups), it is important to consider possible sample bias and potential key differences between the current sample and a clinical population. An important aspect to consider is time since diagnosis; only one participant received their PNES diagnosis within a few months of coming forward to participate in the study (P2), whereas the remaining participants had received

their diagnosis between 1 and 5 years prior to starting the study. On closer inspection of the Facebook groups used to recruit participants, it appeared that recently diagnosed individuals were active on these platforms, however, these individuals did not come forward to participate in the current study. A review of participant research literature in medical settings highlighted that individuals who trusted the recruiter (usually their doctor) and let the recruiter (their doctor) make treatment decisions on their behalf were more likely to take part in research (Cox & Avis, 1996; Ellis, 2000); whereas a lack of understanding of what is required and concerns regarding the proposed research intervention were barriers to recruitment (Cunny & Miller, 1993). Receiving a diagnosis of PNES can be a confusing time for patients, especially if they originally believed the cause of their seizures was physical in nature (i.e. epilepsy) (Baslet & Prensky, 2013), therefore they may be unwilling to accept psychological treatment (the basis of the current study) for their seizures. In addition, the recruiter was not part of the clinical team where prospective participants received their diagnosis, which may have been a barrier to recruiting newly diagnosed individuals; such individuals may have been more willing to take part in the study if recruitment had occurred within specialist clinical settings where other professionals involved in the patient's care had been part of the recruitment process.

A key difference between the current study sample and a clinical population may be time since diagnosis; as only one participant in the current study was recently diagnosed with PNES, there is possible sample bias in the current sample. Another difference between the current sample and a clinical population is the availability of clinical records; in a clinical population, confirmed diagnosis of PNES can be verified, however, within the current sample, the researchers relied on participants understanding of their diagnosis when coming forward to take part in the study and as clinical records were not available to verify it is possible that the results of the study were confounded by other related, but not specific, diagnoses of PNES.

4.3.1.2 *Diagnosis*

VEEG diagnosed PNES is the 'gold standard' in determining PNES, however, of those that have VEEG carried out, only around 85% receive a definitive diagnosis (Benbadis, O'Neill, Tatum, & Heriaud, 2004) (although no test is 100% accurate; Shelley, Trimble, & Boutros, 2008) and in many cases clinician expertise and knowledge are fundamental to receiving a confirmed diagnosis (Higgs, 2008). A strength of the current study was its inclusiveness of participants without a VEEG diagnosis to take part (although a confirmed diagnosis via a PNES specialist was required), making the sample more representative of a PNES cohort. However, this may limit the generalisability of the findings to other PNES research studies, where samples almost exclusively consist of individuals with VEEG confirmed diagnoses of PNES (N. M. Griffith & Szaflarski, 2010).

Previous research studies have acknowledged the large heterogeneity that exists within the PNES population and some authors have argued for the division of PNES patients into different subgroups based on personality profiles, psychosocial histories or PNES aetiology (Reuber, Pukrop, Bauer, Derfuss, & Elger, 2004; Rusch, Morris, Allen, & Lathrop, 2001; Vanderzant, Giordani, Berent, Dreifuss, & Sackellares, 1986). The present study obtained information from participants describing their psychiatric history (in the form of past and current mental health diagnoses), however, an in-depth diagnostic interview was not carried out. The lack of detailed diagnostic information obtained from participants may be regarded as a weakness of the present study, given the evidence pertaining to specific subgroups of PNES, however, this information was collected to ensure the sample was representative of a PNES population, rather than for a detailed analysis of subgroup aetiologic factors. Furthermore, information obtained regarding mental health diagnoses or psychological distress was sufficient enough to group the individual into a 'psychological burden' or 'no burden' group, satisfying the criteria of the RCI and CSC methodology when analysing change on the overall psychological distress measure (Baslet et al., 2010). In addition, the participants that were grouped into psychological burden group (based on psychiatric diagnoses and/or high scores on the psychological distress measure) appeared to benefit the most

from the intervention, regarding changes in quality of life, psychological distress and seizure frequency.

4.3.2 Methodological considerations

All participants were screened prior to commencing the study to ensure the sample was representative of a PNES population. Screening criteria included a minimum number of three seizures in the past month to allow comparison with other treatment efficacy studies (Goldstein, Chalder, et al., 2010; Lundgren et al., 2006). Cut-off scores on other measures, such as quality of life or psychological distress were not used in the screening process; previous studies have highlighted the likelihood of PNES patients under reporting symptoms of emotional or psychological distress (Binzer et al., 2004; Stone et al., 2015), making it difficult to distinguish whether a cut-score should be used and at what point there should be a cut score; indeed, participants came forward to take part in the study despite low scores of psychological distress, suggesting they had concerns regarding their seizures. A limitation of not using cut-off scores in the current study was that some participants were already within a 'functional' range on measures prior to beginning the study and as such, the current study was unable to control for floor or ceiling effects, nor could clinically significant changes be attributed to any changes those participants made (Tingey, Lambert, Burlingame, & Hansen, 1996).

Psychotherapy outcome research is subject to potential researcher allegiance bias (Munder, Brütsch, Leonhart, Gerger, & Barth, 2013). To reduce this bias in the current study, an independent researcher, blind to the results of the study, conducted the final change interview. The reasons for doing so were twofold; firstly, to remove the likelihood that participants would be influenced by demand characteristics (e.g. responses based on pleasing the researcher) and secondly, to reduce the risk of the researcher influencing the outcome of the study (e.g. asking specific/closed questions to receive a particular response), thereby obtaining reliable and unbiased responses from participants.

Although various steps were taken to enhance the scientific rigor of the current study (see relevant sections above) no fidelity checks were carried out to

ensure that the researcher delivering the weekly telephone support/advice adhered to an ACT model (Mowbray, Holter, Teague, & Bybee, 2003), as if a CBT approach was used this could have biased the results of the study. A lack of fidelity checks does not necessarily convey that the researcher did not adhere to an ACT protocol, but the inferences derived from the results may be questionable as a result.

4.3.3 Baseline considerations

The baseline measurement comprised of items taken from the CompACT to measure daily psychological flexibility. As the primary aim of the study was to evaluate psychological flexibility in relation to PNES phenomena, it was essential that a stable baseline of psychological flexibility was achieved so that comparisons could be made with changes in psychological flexibility as the study progressed.

The Daily CompACT (D-CompACT) was a short from version of the CompACT, principally derived to give an estimation of psychological flexibility day-by-day. Items were selected pertaining to the same 3-factor structure of the CompACT and chosen based on highest factor loadings and face validity. However, the form was not subject to independent reviews or interrater reliability/validity checks. Furthermore, correlations between the short form and parent form were not assessed, bringing the reliability and validity of the measure into question (G. T. Smith, McCarthy, & Anderson, 2000). The D-CompACT did reduce burden for participants and appeared to provide a crude estimation of psychological flexibility for which a baseline measurement could be established; furthermore, the full-scale CompACT was administered prior to commencing the study, weekly and at follow-up. However, the limitations of the D-CompACT should be noted and the interpretation of these results should be done so with caution.

Another limitation of the current study was socialisation to the ACT model prior to the intervention. Participants were given information regarding ACT prior to beginning the baseline phase, which may have impacted on scores during that time. One participant (P4) reported changes on outcome measures following

the baseline phase, which may have resulted from the introduction of information about the ACT model, even though no direct intervention had taken place. Improvements following the baseline phase are not uncommon and may reflect external events influencing outcomes (Nock, Goldman, Wang, Albano, & Jellinek, 2004) or may even be the result of the Hawthorne effect (the awareness of being observed and the influence this has on behaviour) (McCambridge, Witton, & Elbourne, 2014).

4.3.4 Considerations for the study duration

The self-help ACT intervention was delivered in sections according the core ACT processes being measured. Of note were the differing lengths of chapters assigned for each intervention phase. For example, the Acceptance process consisted of four chapters, whereas in the last phase, Committed Action consisted of just one chapter. As a result, the Acceptance phase may have been delivered in a 'higher dose' in comparison to other ACT process phases. Furthermore, the majority of participants showed an improvement in psychological flexibility following this phase (apart from P3, deterioration; and P4, no change). P3 and P4's scores on psychological flexibility following the Acceptance phase may have been affected by response-burden therefore improvements in scores following this phase may represent lower response-burden rather than an effect of the ACT intervention. However, P1's improvement (albeit non-significant) following the Acceptance phase (which was the second intervention phase for P1 only), strengthens the assumption that the Acceptance phase contributed to 'higher dosage' rather than an effect of beginning treatment (Hansen, Lambert, & Forman, 2002) (as acceptance was the first intervention phase for all other participants). Furthermore, even if the Acceptance phase contributed to a higher response-burden, it appeared that for the majority of participants, the improvements were a result of the ACT intervention rather than external events (e.g. participant fatigue).

Given the differing lengths of chapters, some participants required longer than one week to complete the reading and exercises for the study. Although the next ACT process chapters were not given until after the previous chapters were completed (to ensure measures collected related to the specific ACT

process in question), there may have been a study effect on the measures collected; for example, if participants had longer to process the information they were given, then this could have impacted on the scores obtained. An example of this occurred for P5 during the self as context phase, where the duration of this phase was over a week longer than for all other participants, as such, the findings during this phase demonstrated a larger effect on all other measures collected within this timeframe. This raised the question as to whether or not having more time to process information results in better outcomes.

Barkham et al. (1996) investigated the duration of therapy and associated patient outcomes, otherwise known as the 'dose-response' effect (for a detailed discussion see Hansen et al., 2002) and found that eight weekly therapy sessions were optimum for ≥50% response improvement rate for psychiatric symptoms, whereas up to sixteen sessions were required for those with interpersonal difficulties, in patients with depression. Differing optimum dose-response rates have been argued depending on the condition being treated; however, in general it appears that the longer the therapy duration, then the better the treatment outcomes (Hansen et al., 2002). In relation to the current study, P5 received the largest 'dosage' of therapy during the self as context and acceptance (see above) phases, which may explain why the largest improvements were observed during the self as context phase and overall. Nonetheless, considering the tiny dosage a guided self-help intervention is likely to convey, it appeared that for the majority of participants, clinically significant improvements were observed on almost all outcomes.

4.3.5 Self-help material modifications

The current study did not modify the self-help materials in any way which has implications for the conclusions that can be drawn from the current study. Firstly, the chapters were not randomised which limits the inferences that can be drawn from reading specific chapters; observed improvements may be the result of carryover effects from previous chapters rather than the chapter of interest. Randomisation of the chapters was withdrawn from the study design following feedback from the first participant who reported difficulty in completing chapters when they referred to previous chapters that had not yet been

received. Secondly, some participants reported that the language used in the self-help material was “too academic” or that some parts of the workbook were not relevant to them (e.g. focussing on anxiety when they didn’t believe they suffered from anxiety) and therefore they may not have engaged with the material as fully as needed. Modification of the ACT self-help workbook to address these limitations may be beneficial for future research examining the utility of this workbook (e.g. allow for randomisation of chapters and ease of reading). However, as the unmodified, original ACT self-help workbook has been utilised in previous SCED research (Roche, Dawson, Moghaddam, Abey, & Gresswell, 2017) and because different sections of the workbook may not be meaningfully distinct, it was felt that randomisation in the current study may undermine the logic of the intervention (which was further supported by feedback from the first participant), therefore, the workbook was utilised in its unmodified form apart from the categorisation of chapters to their applied process.

4.3.6 Specific and non-specific factors

It is important to consider what the effects of the intervention were in relation to the observed outcomes; specifically, the role of other, non-specific factors that may have contributed to the positive outcomes observed in the current study. The SCED makes use of a baseline phase to strengthen the inferences that can be drawn following the intervention, making it possible to draw conclusions about the effectiveness of a specific therapeutic treatment. In the current study, continuous data collected at the baseline phase can be compared to continuous data collected throughout the intervention phase, whereby any changes observed can be inferred as a direct result of the intervention. However, there are several other factors that may have impacted upon outcomes in the current study and these should be considered in relation to the results. First, the researcher had weekly telephone support with each participant and it is possible that a relationship between the researcher and participant developed during these interactions which may have contributed to the positive outcomes observed. Therapeutic relationships are often thought of as ‘non-specific’ therapeutic factors, however, the evidence to suggest that the therapeutic relationship alone is sufficient for symptom and behaviour change is limited

(Priebe & Mccabe, 2008). Whereas good relationships between clinicians and patients has demonstrated participant engagement and adherence to the treatment regimen (McCabe & Priebe, 2004; Priebe & Mccabe, 2008). Furthermore, in relation to self-help, R. Richardson and Richards (2010) found that many self-help books contained therapeutic common factors such as empathy and warmth to establish an alliance with the reader, however, better outcomes for guided self-help, rather than non-guided self-help have been reported, which may reflect the difficulties of incorporating common factors of flexibility and rupture repair (related to developing and maintaining the alliance) in self-help texts, indicating the importance of the therapeutic relationship in treatment outcomes.

Another non-specific factor that may have impacted on outcomes in the current study is the nature of repeated measures assessment. J. P. Sharpe and Gilbert (1998) posit that continuous reassessment may bias results for several reasons; first, because participants want to respond in a socially desirable way; second, because test anxiety decreases over time; and third, because completing self-report measures leads to participant self-awareness (self-monitoring) and prompts them to respond in meaningful or therapeutic ways. In addition, the fact that participants are aware they are being observed can lead to changes in behaviour (e.g. the Hawthorne Effect; McCambridge et al., 2014). Although it is possible that repeated assessment may bias study results, there is limited evidence to suggest this is always the case; studies examining reassessment effects vary and the representativeness of this research is unclear (French & Sutton, 2010; McCambridge et al., 2011). Nonetheless, repeated assessment needs to be considered when drawing conclusions from the current study results.

4.3.7 Generalisability

The sample in the present study consisted of adults with a confirmed diagnosis of PNES (discussion regarding this point has already been outlined in the sampling considerations section), the majority of which were female. This is generally representative of a PNES cohort where women are 3 to 4 times more likely to be affected than men (Schmitz, 2010). Participants with a range of ages

participated in the study, however the study may not be generalisable to children or young people. Furthermore, the inclusion of participants without VEEG confirmed diagnosis of PNES means that comparing the findings to other PNES research may be difficult, however, given that VEEG may be used as confirmation of diagnostic exclusion (i.e. epilepsy), then tentative comparisons can be made across diagnoses, age and gender.

4.4 Clinical relevance

4.4.1 ACT guided self-help

The present study supports the notion that an ACT intervention may be effective for treating individuals with PNES and further support was demonstrated for the delivery of ACT in a guided self-help format. The results of the present study suggest that high levels of intervention (e.g. 1:1 therapy) are not necessary for a successful ACT intervention. Healthcare providers should therefore offer a guided self-help ACT intervention for those with PNES in the first instance (rather than more intensive/formal psychotherapy); not only will this reduce the costs associated with formal psychotherapies, but also allows rapid access to therapy before the condition becomes more chronic (Bodde et al., 2009). In addition, a guided self-help ACT intervention may help reduce the disruption to psychological processes often observed in more intensive/formal 1:1 therapies (as frequent seizures during sessions disrupt these processes) (Howlett & Reuber, 2009).

Non-engagement with psychotherapy has been a documented problem regarding individuals with PNES; Baslet and Prensky (2013) found that only 50% of PNES patients that had accepted a referral to psychology were still engaged in 1:1 sessions at session five. The only predictor for engagement was marriage or ‘living with partner’, which highlighted the difficulties people with PNES have in staying connected with mental health services (Baslet & Prensky, 2013). The positive outcomes reported in the current study provides support for a guided self-hep strategy with a PNES population as it may help patients overcome possible engagement issues with mental health services;

furthermore, the small dose of therapy delivered in a self-help format and the observed efficacy may reflect positive outcomes when individuals with PNES are able to complete a psychological intervention.

4.4.2 Implications for PNES the wider healthcare service context

Patients with PNES are often seen by physical healthcare professionals and neurologists in the first instance and strategies have been published outlining specific protocols in communicating the diagnosis of PNES to patients (Shen, Bowman, & Markand, 1990); this is often a crucial time and when done correctly may have a positive impact on outcomes for patients (Hall-Patch et al., 2010). The involvement of psychological services for patients in receiving the initial diagnosis of PNES has been limited, despite the evidence that rapid access to effective treatment is crucial in preventing conditions becoming chronic (Bodde et al., 2009).

Comparisons can be made between PNES and wider chronic physical health conditions insomuch as there appears to be an association between the delayed or in some cases, the non-involvement of psychological services and high frequency of recurrent visits to physical health services (LaFrance Jr. & Benbadis, 2006; R. D. Richardson & Engel, 2004). Furthermore, evidence from several healthcare utilisation studies suggest that common mental health problems, such as anxiety and depression, contribute to the over-utilisation of physical health services when there is a comorbid long-standing physical health condition, therefore leading to higher overall costs of providing medical care (Auxier, Farley, & Seifert, 2011; Chiles, Lambert, & Hatch, 1999). As such, an approach that is both cost-effective and acceptable to patients with complex physical and mental health issues is welcomed; the current study provides evidence for the feasibility of such a treatment approach.

In line with above research findings, the National Health Service (NHS) has a strategic vision of integrating physical health and mental health services and offering a holistic pathway of care to patients within the next five years (NHS England, 2016). The integration of mental and physical health services aims to improve access to healthcare for patients; previous studies have highlighted the

importance of access to psychological services for patients with PNES but also what some of these barriers might be. As such, the current study provides evidence for the acceptability a guided self-help ACT intervention for patients with PNES and feasibility data as to how this fits within the strategic vision of the NHS.

4.4.3 Screening

Previous studies utilising an ACT approach in a social anxiety and public speaking anxiety populations demonstrated that initially low scores on ACT process measures were negative predictors of improvement following treatment (Dalrymple & Herbert, 2007; Priestly, Dawson, & Golijani-Moghaddam, 2015), however, this was not the case in the current study. Cut off scores on ACT process measures have not previously been determined within the extant literature, therefore it is difficult to establish whether a PNES population have higher initial scores on a psychological flexibility measure than a social anxiety population, furthermore, scores are open to interpretation if cut-offs have not already been predetermined. Nevertheless, initial levels of psychological flexibility as a predictor of treatment outcomes should be considered in future research.

Factors to consider in selecting patients to engage in a guided self-help ACT intervention may include (i) a cut-off score for psychological flexibility, however, no research to date has examined what this cut score should be, and (ii) a cut-off score for distress, as two participants fell within the 'functional' range of distress prior to commencing the study. Caution should be taken in implementing the last point, as although motivation for engagement should be considered, excluding participants who are 'less distressed' in a population where reported emotional/psychological distress varies (Binzer et al., 2004; Stone et al., 2015), may further invalidate and undermine their difficulties (i.e. "you are not distressed enough therefore you can't have any real problems"), thereby reinforcing negative self- and cultural perceptions that PNES is not a real difficulty (Wyatt et al., 2014).

4.5 Future Research

Ideas for future research have been presented in the relevant sections above, however, further discussion of the ideas discussed in the journal paper will be expanded upon here.

4.5.1 Future SCED studies

The distribution of the ACT self-help material in a phased manner may require further evaluation in its utility of being delivered in such a way. The current study appeared to deliver a larger 'dose' of therapy during the Acceptance phase and although this did not appear to negatively influence outcomes from 'participant fatigue', there needs to be some consideration in delivering equal 'doses' of therapy across each phase. Furthermore, the length of some of the chapters restricted participants completing within the one-week timeframe (resulting in positive outcomes for longer exposure to the therapy). The intervention could therefore be delivered over more time (e.g. allowing two weeks for each chapter), or the workbook could be adapted for PNES specifically, removing elements that may not have felt relevant to participants and replacing them with PNES specific examples and metaphors. Self-help ACT books have already been adapted for working with patients with chronic pain (Dahl & Lundgren, 2006) and diabetes (Gregg, Callaghan, & Hayes, 2007) with good reported outcomes (M. Johnston et al., 2010).

In relation to the ACT workbook chapters, future studies that are able to randomise the distribution of chapters would aid and support identification of key ACT processes in mediating change for PNES patients. The current study initially randomised chapters in the study, however, after feedback from the first participant that they found the chapter difficult to follow as it referred to elements from the first chapter, which they had not yet received, a decision was made to distribute the remaining chapters to the first and subsequent participants in sequential order. Furthermore, the utility of a multiple baseline design is that cumulative effect issues were addressed as different psychological processes were delivered in different phases, allowing consideration of key change mechanisms within the ACT approach.

The short-form daily measure used to assess baseline psychological flexibility had questionable reliability and validity, therefore, future studies may wish to use the full measure for psychological flexibility rather than the brief measure derived for the current study (though this would be burdensome for participants if completed daily) or develop/evaluate a reliable and valid short form for psychological flexibility. Furthermore, within the current study, seizure frequency was regarded as a behavioural outcome, which is consistent with other treatment efficacy studies of PNES. However, seizure frequency was not a primary outcome measure of the present study and the philosophy of ACT pertains that valued living can be accomplished despite seizures. As such, future studies may wish to examine other behavioural outcomes that result from an ACT approach. An example of this may be to identify from the participant prior to treatment something that they avoid doing, which would otherwise align with their personal values, as a result of PNES (e.g. going to a restaurant with family). This way, behaviour associated with that task can be monitored and if successful, lends further support for an ACT approach in treating PNES.

A limitation of other treatment efficacy studies for PNES (e.g. CBT) is that long term follow-up data is not always available. The current study employed a follow-up period of one month, however, longer term follow-up would be beneficial in supporting the efficacy of an ACT treatment for PNES should treatment effects persist over time. However, given the improvements already observed in the current study and evidence from chronic pain research demonstrating the long-term treatment effects of an ACT intervention (Hann & McCracken, 2014; McCracken et al., 2007), it is hypothesised that the treatment effects of the current study will be long lasting.

4.5.2 Future research for treatment of PNES

Much of the evidence base concerning psychological treatment for PNES is based on CBT applications with varying degrees of efficacy. To date, one RCT has been conducted demonstrating CBT as an effective treatment for PNES compared to standard medical care (i.e. no psychological intervention), however, more research is necessary to demonstrate mechanisms of action for

the changes observed and comparisons with other psychological interventions. The present study lends support for the treatment of PNES with a guided self-help ACT intervention, in which mechanisms of change have been identified. It appeared that mechanisms of acceptance and cognitive defusion were key elements in facilitating a shift in the successful outcomes observed. However, at this point, only tentative arguments can be made regarding the effect of these mechanisms, therefore future studies with larger samples that monitor the treatment phases of ACT and subsequent outcomes should be implemented.

To date, no RCTs have been conducted assessing the efficacy of an ACT intervention for PNES, however, preliminary findings from the current study demonstrate that the approach may be effective for some individuals with PNES. Further comparisons between CBT and ACT for PNES need to be made, however, the two approaches may be more similar distinct (Arch & Craske, 2008) and a marrying of approaches may be beneficial for a PNES population, however the utility of a combined approach will need further investigation.

4.6 Critical Reflection

The following section will outline my reflections of the research process within scientific, theoretical and ethical dimensions.

4.6.1 Scientific

The use of SCED methodology within my research was something that I was excited to try as it seemed well suited to what I was investigating within my research. Initially, I found the SCED to be a useful tool whereby changes could be tracked over time regarding specific treatment processes which I felt would make a contribution to the scientific research regarding treatment for individuals with PNES. As a PNES population is highly heterogeneous, I felt that a SCED would be extremely advantageous as it allows comparisons of individual differences to be made.

As I progressed with my research, however, I found myself doubting the design I had chosen, not only because I felt overwhelmed with the many aspects associated with the SCED and the analysis, but I became more and more aware of the lack of published treatment-efficacy SCED research and felt down-heartened that the methodology I had chosen to invest a lot of time into may not be seen as valuable by the rest of the scientific community. The SCED is not as scientifically robust as other well documented methodologies, such as RCTs or even group designs, which appeared almost exclusively consistent with treatment efficacy studies; which left me wondering whether my research would have any impact at all. However, it was during the analysis stage of the research that I again came to appreciate the SCED and the inferences that could be drawn from of the intervention. I realised that the SCED had equipped me with skills that I could use in my clinical practice to evaluate my own effectiveness as a practitioner to help me identify what's working and what isn't when working with a client. Therefore, not only was the SCED useful for my research, but is something that I will take forward in my clinical work.

4.6.2 Theoretical

The biggest theoretical challenge for me was in deciding which theoretical model best explained PNES. There were many competing models of PNES and although they all had their strengths, they all appeared limited in some way in their ability to fully explain PNES given some of the differences reported between PNES patients. Although I hoped my research would help 'fill in the gaps', I felt uneasy that it might not and that I would still be wondering, searching, for the 'truth'. I have found this to be the case throughout the course, taking in as many different approaches as possible and weighing them up; as a result, I often find that I am left sitting on the fence, committed to no one approach. In relation to my research, I felt that a more pragmatic approach was necessary and noticed I had much more enthusiasm for my chosen model.

As my research focused on the theoretical application of ACT to PNES, I found myself championing the ACT approach and opposing CBT initially; the differences between them appeared vast in both theory and application. For

example, from an ACT perspective, thoughts are a form of behaviour, whereas from a cognitive stance, thoughts *influence* behaviour; and in terms of application, ACT suggests that changing the context (e.g. private events) in which thoughts occur results in positive changes, whereas CBT suggests that changing the form or content of thoughts is fundamental for effective treatment outcomes. However, during the research process I found myself wondering how different these approaches really were; did separating the thought from the thinker (as in ACT) actually result in changing the form of the thought? And did restructuring thoughts (as in CBT) ultimately alter the context in which they occurred? Following these musings, I wondered whether ACT really was that different to CBT and perhaps my initial opposition to CBT in favour of ACT was foolish. Indeed, it may be that different ways of approaching the same thing will work for different people, however, identifying what approach and for whom requires further investigation.

4.6.3 Ethical

The weekly telephone support with participants was a large factor of the study and although important in assessing participant engagement, it also raised several ethical dilemmas.

My role as a researcher in the study meant that the weekly calls were to support participants in the study, however, there were times when participants had had difficult weeks and wished to speak with me about it in detail; at times, this was not always relevant to the study, however, given the skills I also possessed as a trainee clinical psychologist, I had the ability to contain them. At times, this was particularly difficult as I would find myself formulating their difficulties in my mind and from a therapist standpoint, could have suggested methods to use that might help. However, as my role was researcher and not therapist, there was little I could do apart from direct them back to the self-help materials or signpost them to relevant agencies if necessary.

The ‘push-pull’ of therapist-researcher made me feel very uneasy and I wondered how other researchers dealt with such issues if they were not also

trained therapists. Along the same train of thought, I also wondered whether the boundaries had been blurred between researcher and therapist, as perhaps I had inadvertently invited such issues being brought up as participants knew I was a trainee psychologist. Although I felt slightly relieved that I had the skills to manage such situations as a therapist, I wondered what participants thought of me as a therapist as I did not offer any advice that deviated from the workbook material, in order to preserve the validity of my research. This left me wondering how to approach such dilemmas in the future and perhaps structured boundaries from the outset would have resolved some of the difficulties I faced in this respect.

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Appendix A

Participant Information Sheet

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Participant Information Sheet
(Final version 1.2: 03/08/2016)

Title of Study: **The utility of acceptance and commitment therapy guided self-help for psychogenic non-epileptic seizures**

Name of Researcher(s): Ruth Barrett-Naylor, David Dawson, Mark Gresswell

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

If you are interested in taking part in this study, please let the researcher know and the researcher will arrange a time to discuss this with you further. You are under no obligation to take part when you speak with us, as this contact is to provide you with further information to help you make a decision about whether or not you would like to take part.

This information sheet is designed to inform you of the purpose of the study and what to expect if you decide to take part.

Thank you for your time.

What is the purpose of the study?
We aim to examine the usefulness of acceptance and commitment therapy (ACT) for people with psychogenic non-epileptic seizures (PNES). We think that this is important because at the moment, there are no 'recommended' psychological treatments for people with PNES. ACT is different to other psychological interventions because a reduction in symptoms is not the primary focus. Instead, ACT works by asking the person to look at the coping strategies they use, how these strategies work for them, and helps us make use of different ways of managing difficult experiences in pursuit of the person's life values.

It is thought that living our lives to our values, symptoms become less important and in some cases symptoms may reduce as a result of this. Development of acceptance and awareness of the present moment is thought to guide the person

towards the things they most value in life, and is a key concept in ACT. ACT has been used successfully as a therapeutic intervention in other conditions, such as drug-resistant epilepsy, chronic pain, depression and anxiety. It is thought that an ACT intervention may help those with PNES lead lives they find personally more meaningful, despite their seizures.

Why have I been invited?
You are being invited to take part because you are an adult with a confirmed diagnosis of PNES. We are inviting at least 6 participants like you to take part.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be emailed a copy of this information sheet to keep and will be asked for your informed consent. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen if I don't want to carry on with the study?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to me if I take part?
If you agree and consent to take part in the study, your main involvement will be to complete a self-help book. The self-help book is a published book called "Get out of your mind and into your life" by Steven Hayes and Spencer Smith and has been used in other clinical studies to help treat conditions such as anxiety, depression and chronic pain. However, please do not purchase this book during the study period to read ahead as this would interfere with the study.

The study will involve completing exercises from the self-help book and you will receive a different chapter of the book each week. You will also receive telephone support from the researcher each week to get your feedback on the experience of completing the self-help exercises from the book chapter. As part of the study, you will be asked to complete 3 brief questionnaires every day and also up to 6 questionnaires once each week. All questionnaires will be submitted to the researcher online.

Before you are able to start the study, you will be asked to complete an online screening questionnaire, which will take no longer than a few minutes to complete. If you do not meet the screening criteria, then you will not be able to take part in the study. If you do meet our eligibility criteria you will be invited to complete some more brief questionnaires. The researcher will then email (or post) you some reading material about ACT to read before you receive the self-help material. You will then begin the study and be asked to complete the daily questionnaires (as mentioned above) every day. After 1-2 weeks of completing the daily and weekly measures, you will receive the first chapter of the self-help book. From this point on you will continue to complete the daily and weekly measures and will be emailed or posted a new chapter of the book each week, and receive telephone support each week from the researcher. **N.B.** Before

commencing you will be asked what times are convenient to receive the weekly telephone contact from the researcher. To ensure accurate recording and collation of questionnaire data, you will be sent daily text message reminders; the researcher will ask you what times of the day are most convenient to send you these reminders.

The study length is estimated to take 8 weeks (you will be contacted again 1 month after the end of the intervention for further questionnaires to be completed). The time taken to complete the daily and weekly questionnaires is estimated to take a couple of minutes each. Reading time for the self-help chapters is dependent on your own reading speed; however the chapters are generally between 9 to 20 pages long. Participants will receive one, two, or three chapters each week.

Below are the main procedural points for taking part in the study:

Register interest in taking part with the researcher, leaving a contact number and convenient time to call

↓

The researcher will contact you to discuss the study with you in more detail

↓

If you want to take part, you will be given the details for the website where you must give your consent for taking part in the study. You will then complete the online screening questionnaire.

↓

If you pass the screening criteria, you will be asked to complete some more questionnaires. An overview of ACT will be emailed to you to familiarise yourself with ACT before you begin the intervention.

↓

For the next 1-2 weeks you will complete the daily questionnaires every day and the weekly questionnaires each week. You will be sent text message reminders to complete these. These will all be completed online.

↓

After 1 or 2 weeks you will be emailed or posted the first chapter of the self-help book to work through. At the same time, you will continue to complete the daily and weekly questionnaires. The researcher will speak to you each week (via telephone) to get feedback on your experience of the intervention.

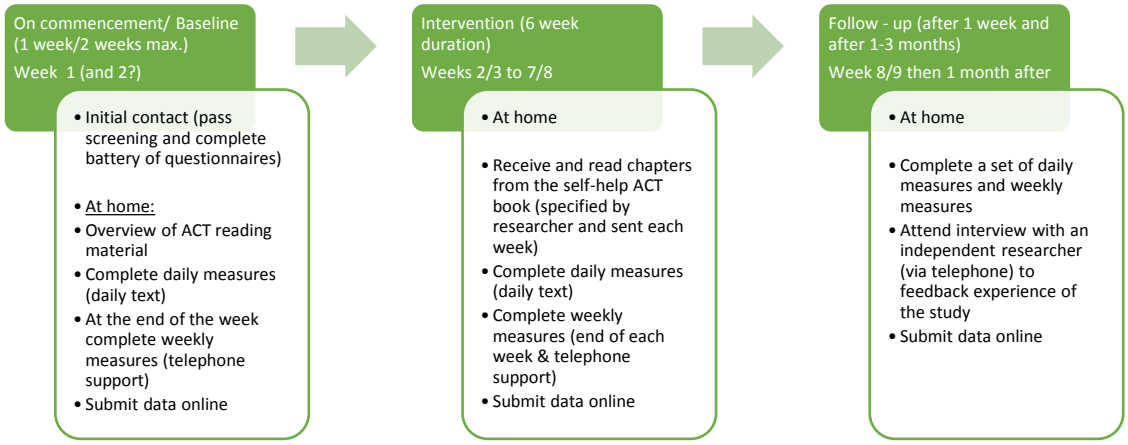
↓

This procedure will be repeated for the next 5 weeks, so that in total, you will have received 6 weeks' worth of the ACT intervention (not including the 1-2 week introduction to ACT).

A week after you have completed the intervention you will be asked to complete the questionnaires again (once).

A month after the intervention you will be asked to complete the questionnaires again (once) and will be invited to take part in a follow-up telephone interview with an independent researcher to feedback your experience in taking part in the study.

Below is a flow chart of the different phases of the study:



The 1 to 2 week period at the beginning is to establish stability on the daily questionnaires you complete, it is expected to last a week, however it may take up to 2 weeks before a stable baseline can be reached. If a stable baseline is not reached after 2 weeks, then your participation in the study will no longer be required; this is because it will then be unlikely that a stable baseline can be reached within the time frame of the expected study duration and the researcher will let you know if this is the case. If, however, a stable baseline has been reached within the allowed timeframe, you will receive your first chapter(s) from the ACT self-help book to complete during the week and will follow the procedure outlined above.

Expenses and payments

Because of your time and commitment for participation in the study, you will be paid a total of £40. You will receive £5 per week for up to 6 weeks (for the intervention process) and an additional £10 when you complete the follow up (1 month after the intervention) and have the phone interview with the independent researcher.

What are the possible disadvantages and risks of taking part?
If you decide to take part in the study you will be required to complete daily and weekly questionnaires and work through the self-help material each week which will take up some of your time. While taking part in the study it will be important for you to maintain a balance between completing these tasks, your personal work and time for relaxation. It is unlikely that the intervention will negatively impact you, however it is important to consider that your seizures may become worse; if this happens the researcher will speak with you about this, signpost you to relevant services or agencies if needed, and discuss with you your involvement in the rest of the study.

The study is an experimental study, and although it is hoped that the intervention will have a positive effect, there is a possibility that it will not benefit you or that your condition may worsen. In addition, the aim of the ACT intervention is not to reduce seizures (although some research has shown that symptoms may reduce as a secondary effect of the intervention). Therefore, it is important for you to consider that there may be no positive changes in the frequency of your seizures.

What are the possible benefits of taking part?
You may find that the intervention improves some areas of your life, such as your social life, work and psychological well-being. It is possible that the intervention may have a positive effect on the frequency of your seizures, however, this is not the primary aim of the study, nor can we promise that the intervention will impact your seizures at all. We cannot promise the study will help you but the information we get from this study may help explain how it may help in the future.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting University of Nottingham Faculty of Medicine & Health Sciences (FMHS) Research Ethics Administrator, c/o the School of Medicine Education Centre, B Floor Medical School, QMC Campus, Nottingham University Hospitals, NG7 2UH e-mail: louise.sabir@nottingham.ac.uk.

Will my taking part in the study be kept confidential?
All information collected about you will be kept strictly confidential throughout the lifetime of the study, unless you say something to suggest that you or someone else is at risk of harm. Where possible, the researcher will discuss this with you in the first instance if this arises and may need to report any concerns to the appropriate persons (e.g. police)

If you take part in the study you will be assigned a randomised generated numerical code which will be used to identify you throughout the data collection and analysis stages of the study. Your code will be stored on a secure, password protected memory stick which will remain in a locked cabinet in the University of Nottingham.

If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham and University of Lincoln who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the university will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for one year after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All research data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen to the results of the research study?
The study will be submitted as part of a thesis for a Doctorate in Clinical Psychology at the University of Nottingham. The study may also be submitted for publication by scientific journals or the results of the study may be presented at conferences. No personal or identifiable information about you will be used in the presenting or publication of the study. You will receive a summary of the overall study once it has been completed.

Who has reviewed the study?
All research in the University of Nottingham is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Nottingham, Faculty of Medicine & Health Sciences Research Ethics Committee.

What to do now?
If you would like to take part in the study, please contact the researcher to arrange a time to discuss this with you further. If you decide that you would like to participate in the study, the researcher will require your informed consent, which will be gained online prior to completing the screening questionnaire.

Further information and contact details
If you have any questions or concerns regarding the research study, please contact the researcher using the contact details below.

Researcher
Name: Ruth Barrett-Naylor
07874127422
Email: msxvrb@nottingham.ac.uk

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Appendix B

Consent Form

(Final Version 1.2: date 21/19/2016)

Title of Study: The utility of acceptance and commitment therapy guided self-help for psychogenic non-epileptic seizures

REC ref: O10052016 16038 SoM DClinPsy
Name of Researcher: Ruth Barrett-Naylor

Thank you for considering participation in this study. Please click here (hyperlink) to read the participant information sheet carefully before proceeding.

I confirm that I have read and understood the participant information sheet regarding the above study.

I confirm that I have had the opportunity to ask questions in regard to participation in the above study and that my questions have been answered fully

I understand that I am free to withdraw from this study at any time without giving reason

I understand that if I choose to withdraw from the study, the information collected up until that point cannot be erased and therefore may still be used in the analysis of the research study

I understand that my personal details will be kept confidential and no identifiable information will be used in the written report for this research

I understand that data collected will be analysed by the researcher but may also be shared with authorised individuals from the University of Nottingham and the University of Lincoln

I give permission for the data collected from my participation in the study to be analysed, reported and published

I confirm that I am above the age of 18

□ Yes, I have understood the information and consent to taking part in the study
□ No, I no longer wish to take part in the study

Appendix C

Daily Questionnaire

1. How many psychogenic non-epileptic seizures have you had in the past 24 hours?

2. How many epileptic seizures have you had in the past 24 hours? (if not applicable state n/a)

3. What type of **non-epileptic seizures** did you have in past 24 hours? How long did they last **in total**?

Please specify whether duration is in 's' (seconds), 'm' (minutes), 'h' (hours).
Please enter the total duration of that type of seizure (e.g. 2 convulsive seizures lasting 2 minutes in total and 1 dissociative lasting 3 minutes)

Please tick all that apply (or leave blank if not applicable to you today)

- ❑ Convulsive (total duration= _____)
- ❑ Dissociate/absent (total duration= _____)
- ❑ Blackout (total duration= _____)
- ❑ Other (please describe and total duration= _____)

Please use the space below to add any further details about your non-epileptic seizures (e.g. any triggers) or information about today that you think would be useful for me to know.

4. In the **past 24 hours** I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)

- ❍ Never
- ❍ Sometimes
- ❍ Often
- ❍ Always

5. In the **past 24 hours** I felt that life was meaningless

- ❍ Never
- ❍ Sometimes
- ❍ Often
- ❍ Always

6. In the **past 24 hours** I was intolerant of anything that kept me from getting on with what I was doing

- ❍ Never
- ❍ Sometimes
- ❍ Often
- ❍ Always

Please rate how the following statements applied to you in the **past 24 hours**

7. Even when doing the things that matter to me, I find myself doing them without paying attention

- ❍ Strongly disagree
- ❍ Moderately disagree
- ❍ Slightly disagree
- ❍ Neither agree nor disagree
- ❍ Slightly agree
- ❍ Moderately agree
- ❍ Strongly agree

8. I rush through meaningful activities without being really attentive to them

- ❍ Strongly disagree
- ❍ Moderately disagree
- ❍ Slightly disagree
- ❍ Neither agree nor disagree
- ❍ Slightly agree
- ❍ Moderately agree
- ❍ Strongly agree

9. I work hard to keep out upsetting feelings

- ❍ Strongly disagree
- ❍ Moderately disagree
- ❍ Slightly disagree
- ❍ Neither agree nor disagree
- ❍ Slightly agree
- ❍ Moderately agree
- ❍ Strongly agree

10. My values are really reflected in my behaviour

- ❍ Strongly disagree
- ❍ Moderately disagree
- ❍ Slightly disagree
- ❍ Neither agree nor disagree
- ❍ Slightly agree
- ❍ Moderately agree
- ❍ Strongly agree

11. Thoughts are just thoughts - they don't control what I do

- ❍ Strongly disagree
- ❍ Moderately disagree
- ❍ Slightly disagree
- ❍ Neither agree nor disagree
- ❍ Slightly agree
- ❍ Moderately agree
- ❍ Strongly agree

12. I behave in line with my personal values

- ❍ Strongly disagree
- ❍ Moderately disagree
- ❍ Slightly disagree
- ❍ Neither agree nor disagree
- ❍ Slightly agree
- ❍ Moderately agree
- ❍ Strongly agree

Appendix D

Ethical Approval Documents

Faculty of Medicine and Health Sciences

Direct line/e-mail
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Louise.Sabir@nottingham.ac.uk

Research Ethics Committee
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

15th June 2016

Ruth Barrett-Naylor
Trainee Clinical Psychologist Trent DClinPsy student
Division of Psychiatry and Applied Psychology
B Floor, Yang Fujia Building,
School of Medicine
Jubilee Campus,
Wollaton Road Nottingham
NG8 1BB

Dear Ruth

Ethics Reference No: O10052016 16038 SoM DClinPsy **– please always quote**
IRAS Project ID: 200041
Study Title: The utility of acceptance and commitment therapy guided self-help for psychogenic non-epileptic seizures.
Short Title: Utility of ACT Self-help for PNES
Chief Investigator/Supervisor: David Dawson, Research Clinical Psychologist, Trent Doctorate in Clinical Psychology, College of Social Science, Mark Gresswell, Co-Director Trent Clinical Psychology Training Programme, Department of Clinical Psychology, University of Lincoln
Lead Investigators/student: Ruth Barrett-Naylor, Doctorate in Clinical Psychology Student, Psychiatry and Applied Psychology, School of Medicine- Joint Nottingham/Lincoln programme.
Type of Study: PhD Student Project, qualitative/quantitative, survey
Proposed Start Date: 05/2016 **Proposed End Date:** 31 January 2017 9 mths
No of Subjects: 6 **Age:** 18+yrs

Thank you for submitting the above application which was considered by the Committee at its meeting on 10 May 2016 and the following documents were received:

Utility of ACT self-help for PNES:

- FMHS Research Ethics Application form dated 22/04/2016
- Protocol Final version 1.0 date 25/05/2016
- ACT Self-help "Get out of your mind and into your life" by Hayes and Smith (2005)
- Invitation/advert to be placed on NEAD facebook group Final v1.0 22/04/2016
- Participant Information Sheet Final version 1.0 25/05/2016
- Consent Form Final version 1.0 25/04/2016

These have been reviewed and are satisfactory and the study is approved.

Approval is given on the understanding that the conditions set out below are followed:

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a

form).

2. You must notify the Chair of any serious or unexpected event.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely



Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Faculty of Medicine and Health Sciences

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Research Ethics Committee
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NG7 2UH

27th June 2016

Ruth Barrett-Naylor
Trainee Clinical Psychologist Trent DClinPsy student
Division of Psychiatry and Applied Psychology
B Floor, Yang Fujia Building,
School of Medicine
Jubilee Campus,
Wollaton Road Nottingham
NG8 1BB

Dear Ruth

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Lead Investigators/student: Ruth Barrett-Naylor, Doctorate in Clinical Psychology Student, Psychiatry and Applied Psychology, School of Medicine- Joint Nottingham/Lincoln programme.

Type of Study: PhD Student Project, qualitative/quantitative, survey

Proposed Start Date: 05/2016 **Proposed End Date:** 31 January 2017 9 mths
No of Subjects: at least 6 **Age:** 18+yrs

Thank you for notifying the Committee of amendment no 1 23 June 2016 in summary as follows:

- Two Minor changes to the Participant Information sheet as detailed in e-mail dated 23 June 2016.

These have been reviewed and are satisfactory and the study amendment no 1: 23/06/2016 is noted and approved.

Yours sincerely

pp Lamagadni

Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Faculty of Medicine and Health Sciences

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Research Ethics Committee
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4th August 2016

Ruth Barrett-Naylor
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NG8 1BB

Dear Ruth

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IRAS Project ID: 200041
Study Title: The utility of acceptance and commitment therapy guided self-help for psychogenic non-epileptic seizures.
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Type of Study: PhD Student Project, qualitative/quantitative, survey

Proposed Start Date: 05/2016 **Proposed End Date:** 31 January 2017 9 mths
No of Subjects: at least 6 **Age:** 18+yrs

Thank you for notifying the Committee of amendment no 2 26 July 2016 in summary as follows:

- Change to Inclusion criteria: term changed to “Confirmed diagnosis” to capture those diagnosed by other means than by a neurologist and widen recruitment. Inclusion added: participants that have current counselling which is not directly related to their seizures can participate with monitoring provided to establish if this is a confounding variable.
- Recruitment: posting on other non-epileptic fit disorder facebook pages to improve recruitment.
- Consent Form: statements revised to be more accessible for participants e.g. shorter but same information.
- Sample size: changed to “at least 6” so that more than 6 participants can be recruited in case of participant attrition.

and the following documents were received:

Utility of ACT self-help for PNES:

- Notice of Amendment Form no 2 dated 26/07/2016
- FMHS Research Ethics Application form version 2 dated 26/07/2016
- Protocol Final version 2.0 date 26/07/2016
- Participant Information Sheet Final version 1.2. 03/08/2016

These have been reviewed and are satisfactory and the study amendment no 2: 26/07/2016 is approved.

Approval is given on the understanding that the conditions set out below are followed:

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).

2. You must notify the Chair of any serious or unexpected event.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

pp Lamiegatori

Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

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Queen's Medical Centre Campus
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22nd September 2016

Ruth Barrett-Naylor
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Jubilee Campus,
Wollaton Road Nottingham
NG8 1BB

Dear Ruth

Ethics Reference No: O10052016 16038 SoM DClinPsy **– please always quote**
IRAS Project ID: 200041
Study Title: The utility of acceptance and commitment therapy guided self-help for psychogenic non-epileptic seizures.
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Chief Investigator/Supervisor: David Dawson, Research Clinical Psychologist, Trent Doctorate in Clinical Psychology, College of Social Science, Mark Gresswell, Co-Director Trent Clinical Psychology Training Programme, Department of Clinical Psychology, University of Lincoln

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Type of Study: PhD Student Project, qualitative/quantitative, survey

Proposed Start Date: 05/2016 **Proposed End Date:** 31 January 2017 9 mths
No of Subjects: at least 6 **Age:** 18+yrs

Thank you for notifying the Committee of amendment no 3 21 September 2016 in summary as follows:

- The consent process outlined in section 8 of the application form did not accurately describe the actual consent process: participants submit informed consent anonymously online. The application form, protocol and consent have been revised accordingly.

- The protocol has been proof read and it was noted that references to procedures and sections intended for a clinical trial study had been left in error. These have been removed/changed accordingly as detailed in the notice of amendment form.

- Addition of a participant de-brief sheet to be emailed participants on completion of the study.

and the following documents were received:

Utility of ACT self-help for PNES:

- Notice of Amendment Form no 3 dated 21/09/2016
- FMHS Research Ethics Application form version 2.1 dated 21/09/2016
- Protocol Final version 2.1 date 21/09/2016

- Consent Form final version 1.2 date 21/09/2016
- Participant Debrief Sheet Final version 1 21/09/2016

These have been reviewed and are satisfactory and the study amendment no 2: 26/07/2016 is approved.

Approval is given on the understanding that the conditions set out below are followed:

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).

2. You must notify the Chair of any serious or unexpected event.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

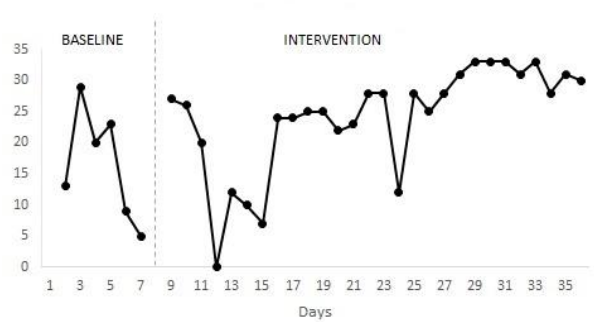


Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

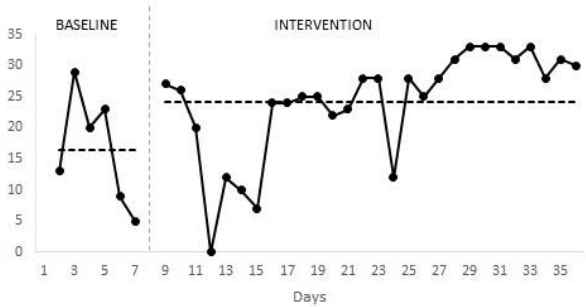
Appendix E:

SCED parameters of daily psychological flexibility

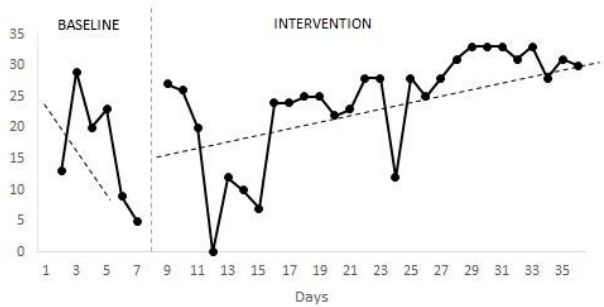
a. raw data



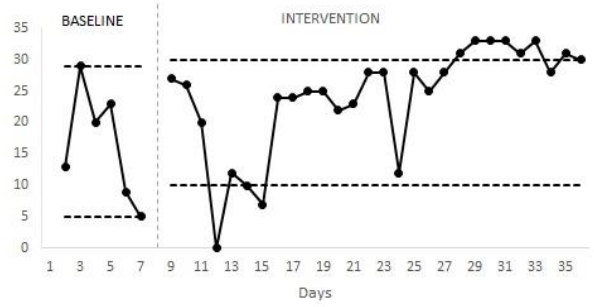
b. central tendency



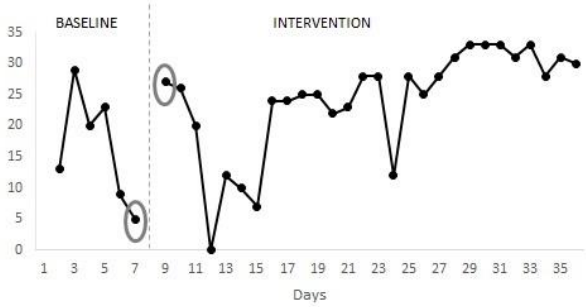
c. linear trend



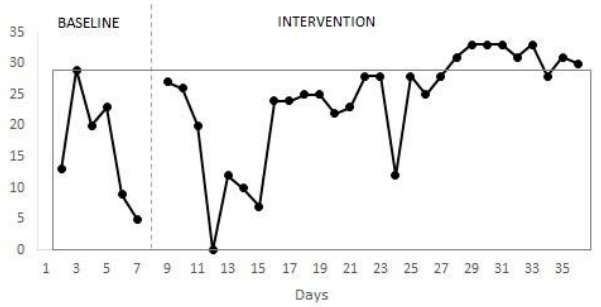
d. variability (trimmed range)



e. point of change



f. overlap region



Appendix F

Change interview schedule

(*Introduce self and remind participant about confidentiality*)

1. Can you please tell me how you found the intervention / workbook?
2. Was the book easy to read and understand? (If not, why?)
3. Would you recommend this book to others?
4. Were there any chapters in the book you found helpful?
5. What would you say has changed for you?
6. In your opinion were these positive or negative changes?
7. Can you rate how surprised you were by these changes from 1 (not surprised by the changes) to 5 (surprised by the changes)?

1	2	3	4	5
Not surprised by the changes		Neutral		Surprised by the changes

8. Please rate how likely it is that these changes were a result of reading the workbook from 1 (not likely) to 5 (likely)?

1	3	5
Not likely	Neutral	Likely

9. Rate the importance of these changes from 1 (not important) to 5 (important)?

1	3	5
Not important	Neutral	Important

10. Please rank the following areas in order of importance to you currently (1 most important, 7 least important) *(read areas first then ask participant to order them)*

Energy (tiredness)	Mood
Daily activities	Mental function
Medication effects	Worry about seizures
Overall quality of life	

11. Have you noticed a change in your seizures or factors associated with your non-epileptic seizures? And if so, it what area? (seizures, depression, anxiety, stress, quality of life)
12. Did any external events occur during the study time period? (In the areas of work or relationships etc. for example). If so, do you think this may have had an effect?
13. Can you tell me how you found the researcher support?

Any additional comments?

The utility of Acceptance and Commitment Therapy guided self-help for Psychogenic Non-Epileptic Seizures

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Ruth Barrett-Naylor, Dr David Dawson and Dr Mark Gresswell
Trent Doctorate in Clinical Psychology

UNIVERSITY OF LINCOLN

Background

Psychogenic non-epileptic seizures (PNES) are a relatively common condition thought to be the result of underlying psychological processes [1]. PNES is associated with high levels of psychological distress, reduced quality of life, reduced functionality and high levels of avoidance [2,3]. Despite the prevalence and potentially debilitating impact of PNES on individuals, no specific treatments have been suggested.

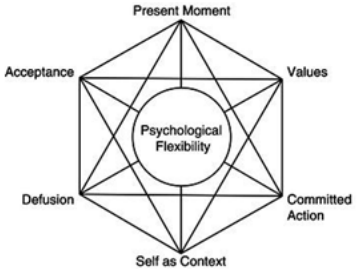
Current treatments for PNES tend to focus on seizure control rather than improving psychological wellbeing and quality of life [4], whereas it may be argued that engagement in overt control of seizures may be damaging [5]. Furthermore, engagement in formal 1:1 psychotherapy can be difficult for this patient group, due to disruptions in psychological processes as a result of seizures within sessions [6].

A guided self-help ACT intervention may help people with PNES engage in meaningful activities and improve their quality of life despite their seizures [7]. Furthermore, if specific ACT processes are identified as key mechanisms of change then this has implications for clinical practice.

Method

The current study used single case experimental design (SCED) and participants were recruited from PNES specific social media sites.

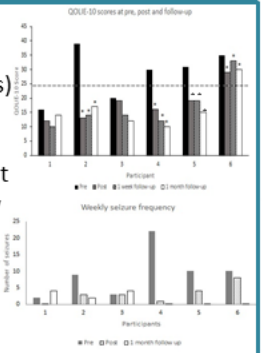
Six participants that had ≥ 3 seizures in the past month, had a confirmed diagnosis of PNES, were not currently having psychological treatment and were willing to read chapters from the self-help book for over six weeks were invited to take part in the study.

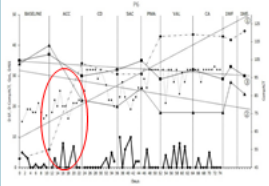


Participants completed a battery of questionnaires before the baseline phase and then after every phase of the intervention. Daily measures of psychological flexibility and seizure frequency were reported throughout the study. After the baseline phase, participants completed a different ACT process chapter from the book *'Get out of your mind and into your life'* in each intervention phase. Participants were followed-up one week and one month after completing the study.

Results

All participants displayed an increase in quality of life (demonstrated by low scores) following the intervention. This change was reliable in 4 cases and clinically significant in 3 cases. Seizure frequency had also decreased significantly after the 1 month follow-up in 4 cases.





In the majority of cases, psychological flexibility, psychological distress and quality of life improved following the acceptance/ cognitive defusion phase of the intervention.

Implications

Self-help interventions may be a cost effective way of treating people with PNES; it addresses engagement issues and appeared an acceptable intervention for people with PNES.

Openness to Experience processes (acceptance and defusion) appeared to be key mechanisms in improving quality of life and psychological distress. Valued action processes appear important in behavioural outcomes.

References:
[1]Marchetti RL, et al. Psychiatric diagnoses of patients with psychogenic non-epileptic seizures. Seizure 2008;17:247–53.
[2]Testa SM, et al. Mood, Personality, and Health-related Quality of Life in Epileptic and Psychogenic Seizure Disorders. Epilepsia 2007;48:973–82.
[3]Goldstein LH, Mellers JDC. Ictal symptoms of anxiety, avoidance behaviour, and dissociation in patients with dissociative seizures. J Neurol Neurosurg Psychiatry 2006;77:616–21.
[4]Goldstein LH, et al. Cognitive behaviour treatments. In: Schachter SC, LaFrance Jr. WC, editors. Gates and Rowan's Nonepileptic Seizures, Cambridge Univ. Press; 2010, p.281–8.
[5]Hayes SC, et al. Acceptance and Commitment Therapy: Model, processes and outcomes. Behav Res Ther 2006;44:1–25.
[6]Howlett S, Reuber M. An augmented model of brief psychodynamic interpersonal therapy for patients with nonepileptic seizures. Psychother Theory, Res Pract Train 2009; 46: 125–38.
[7]Baslet G, Hill J. Case report: Brief mindfulness-based psychotherapeutic intervention during inpatient hospitalization in a patient with conversion and dissociation. Clin Case Stud 2011;10:95–109.